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ORIGINAL ARTICLE – BREAST ONCOLOGY

'Taking Control of Cancer': Understanding Women's Choice for Mastectomy

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ABSTRACT

Purpose. Rates of both unilateral (UM) and contralateral prophylactic mastectomy (CPM) for unilateral early-stage breast cancer (ESBC) have been increasing since 2003. Recent studies suggest that this increase may be due to women choosing UM and CPM because of fear. We conducted an in-depth qualitative study to identify those factors influencing a woman's choice for more extensive surgery.

Methods. Semi-structured interviews were conducted with breast cancer patients to examine the experiences, decision making, and choice of UM ± CPM for the treatment of ESBC. Purposive sampling identified suitable candidates for breast-conserving therapy (BCT) who underwent UM ± CPM. Interviews were guided by grounded theory methodology, and constant comparative analysis identified key concepts and themes.

Results. Data saturation was achieved after 29 interviews. 'Taking control of cancer' was the dominant theme. Fear of breast cancer was expressed at diagnosis and remained throughout decision making. Personal experiences of family or friends 'living with cancer' were the most influential source of information during the decision-making process. Fear translated into an overestimated risk of recurrence, contralateral breast cancer (CBC), and death. Despite surgeons discussing equivalent survival with BCT, UM ± CPM patients believed that by choosing UM ± CPM they would eliminate recurrence, CBC and live longer. By choosing more extensive surgery, women were actively trying to control cancer outcomes as more surgery was believed to offer greater survival.

Conclusions. Women seek UM and CPM to take control of cancer and manage their fear. It is important for surgeons to understand how personal experiences shape women's choice for UM ± CPM to facilitate informed decision making.

In 1990 the National Institutes of Health consensus statement indicated that "breast conservation treatment (BCT) is an appropriate method of primary therapy for the majority of women with early-stage breast cancer (ESBC) (stage 1/2) and is preferable because it provides survival rates equivalent to those of mastectomy while preserving the breast".[1] Before the release of this statement the majority of patients were treated with unilateral mastectomy (UM); however, after 1990 the rates of mastectomy markedly decreased.[2–5]

Recently, numerous studies have documented the increasing use of both UM and contralateral prophylactic

The study findings have been presented as abstracts at the American Society of Clinical Oncology (ASCO) Annual Meeting in Chicago (June 2013), the ASCO Breast Cancer Symposium in San Francisco (September 2013), the Canadian Association of General Surgeons Annual Meeting, (September 2013), and the ASCO Quality Care Symposium in San Diego (November 2013).

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mastectomy (CPM) for unilateral ESBC in women who are not at high risk of developing a contralateral breast cancer (CBC).[6–14] Those patients who are considered to be at high risk of developing a CBC include those with a personal or familial diagnosis of BRCA1/2, or other known genetic mutations, including PTEN and P53; a personal history of ovarian cancer; a personal history of chest wall radiation; and a strong family history of breast or ovarian cancer as defined by the National Comprehensive Cancer Network (NCCN) guidelines.[15,16]

Nationwide studies using the Surveillance, Epidemiology, and End Results registries and the National Cancer Database demonstrated a 10 % rise in UM rate and 150 % rise in CPM rates across women of all ages with ESBC.[8,11,13] While surgeon, patient, and system factors have been associated with the increased rates, they do not describe why this increase is occurring.[17–24] Young, White, educated women of higher socioeconomic status have been reported to choose mastectomy; however, quantitative studies are unable to describe why women are making this choice.[7,8,11,21,25] To further understand the current trends and the role that women play in the increasing mastectomy rates, we conducted a qualitative study exploring patients' perspectives on decision making for ESBC and women's choice for mastectomy.

METHODS

Sampling and Recruitment

Women who had undergone either UM or UM + CPM within the previous 9–12 months (between January 2010 and January 2011) were identified from five prospectively collected breast cancer databases from surgical centers (three academic, two community centers) in the Toronto area, Ontario, Canada. Chart review was then conducted to ensure that participants had ESBC, were not high-risk of developing a CBC, and were suitable candidates for BCT (patients were excluded if they were pregnant at the time of treatment, had bilateral breast disease, or had absolute or relative contraindications for radiation therapy or BCT as defined by NCCN treatment guidelines[26]). Participants were purposively sampled from these databases, ensuring they varied in age and ethnicity and that comparable numbers of women who underwent UM and UM + CPM were recruited from each center. Purposive sampling is a standard qualitative technique where participants are selected based on having both undergone the experience and to reflect the diversity within a given population.[27,28] This provided a wide range of motivations and perspectives on the surgical decision-making process. Our goal was to interview two to three participants from each surgical category (UM or UM + CPM) from each surgical center. Initial contact with patients was made via a standardized letter inviting their participation in the study. The study was reviewed and approved by the Institutional Ethics Review Boards.

Data Collection

Grounded theory (GT) methodology directed the generation of the interview guide, data collection, and data analysis.[29–31] A conceptual framework was developed from a systematic literature review to aid the design of the interview questions. Four pilot interviews were conducted in-person, audio-recorded, transcribed verbatim, and then discussed among the research team (AMC, NNB, MIF, and FCW; AMC is a PhD candidate and a resident trainee in general surgery, NNB is a content expert in surgical oncology and a practising general surgeon, MIF is an expert in qualitative research who focuses on oncology with emphasis on breast cancer, and FCW is a content expert in surgical oncology, a practising breast surgeon, and an expert in qualitative research). The interview guide was then adjusted to ensure all areas of interest were addressed. One-on-one in-person interviews were audiotaped and performed by a single interviewer (AMC under the guidance of FCW). Saturation was reached after 29 interviews; this occurs when key concepts begin to recur and no new concepts emerge from the data.[32] As saturation is often reached between 12 and 20 interviews in a heterogeneous population, a sample size of 29 is substantial in qualitative research.[33]

Data Analysis

Interviews were transcribed verbatim and GT was used to analyze the data. Constant comparative analysis is an iterative approach which involves multiple readings of the transcripts; simultaneous data collection and analysis generates a coding schema reflecting unique ideas.[29,31,34] Analysis of the schema allows similar concepts to be grouped together into larger themes.[29,30,34] Interviews were coded independently by two investigators, findings were discussed with the entire research team, and consensus of interpretation was achieved.

RESULTS

Patients and Interviews

Forty individuals (eight from each center) were invited to participate in the study. Ten patients declined participation: four could not conduct an interview in English, two

TABLE 1 Patient characteristics

	Unilateral mastectomy ($n = 15$)	Contralateral prophylactic mastectomy ($n = 14$)
Location of surgery		
Academic cancer centre	6	7
Academic non-cancer centre	6	5
Community centre	3	2
Disease stage		
1	9	6
2	6	8
Age (years)		
Range	42–84	37–69
Median	56	46
Reconstruction		
Yes	3	8
No	12	6

refused due to disease progression, one had died, two had moved away, one was ineligible, and one agreed but dropped out of the study. Informed consent was obtained from the remaining 29 participants. Interviews took place between September 2010 and January 2012, and the median interview time was 71 min (range 50–91).

Median participant age was 55 years (range 36–84). Fifteen participants underwent UM (three participants from each center), and 14 participants underwent UM + CPM (three participants from four centers, and two participants from one center). Eighteen participants were treated at academic centers, and 11 at community centers. All patients had ESBC (Table 1).

Themes

Decision-Making Experience

1. *Cancer diagnosis* All patients stated that the diagnosis of cancer was received with shock and fear, making comments such as "I was sure that my body was rampaged by cancer I was so panicked" (participant #2) (Table 2).
2. *Surgical consultation and discussion of treatment options* All patients recalled being informed that BCT and UM are equivalent treatment options for ESBC, and most recalled their surgeon stating that BCT and UM results in the same survival. The advantages and disadvantages of both BCT and UM were also routinely described. While patients were aware that they would require radiation treatment (RT) after breast-conserving surgery, they were also informed that surgical choice would not impact the need for hormonal and chemotherapy. In this non-high-risk population, the discussion around CPM was always initiated by the patient. Surgeons did not recommend CPM, and the patients were informed that having a CPM would not improve long-term survival. Surgeons actively discouraged CPM in this non-high-risk population with no medical indication. Women who chose CPM reported being discouraged from this decision by their surgeons. "She didn't want me to do that at all. She said 'It's not going to extend your life (#13)" (Table 2).
3. *Sources of information* All patients described the healthcare team as an information source. However, patients' most valued sources of information were stories from personal experiences of family or friends living with cancer. Patients described witnessing 'suffering though cancer', which left a lasting impression. The most influential of these experiences were loved ones who had been 'lost to breast cancer' I had two friends die within a year previous from breast cancer. They said 'I wish I had just taken them off" (#26) (Table 2).
4. *Understanding of recurrence, CBC and survival* Patients felt that they were at very high risk of developing an ipsilateral recurrence, a CBC, and the 'spread' of their cancer as distant metastasis, believing these events to be inevitable: "if there's breast tissue left there it's coming back" (#1) (Table 2). Patients believed there was an unavoidable stepwise progression between these events, with ipsilateral recurrence and/or CBC leading to metastasis and subsequently death. While patients were counseled that their index case of cancer was the most likely cancer to affect long-term survival, women expressed disproportionate concerns over the cancers that 'might' occur. "I'm not worried about my survival from this (treated side) - I'm worried about the other side" (#3) (Table 2).

Reasons for Mastectomy

1. *Choosing unilateral mastectomy* Certainty of the high risk of recurrence and death resulted in participants choosing UM to eliminate this risk. "I don't want to live in the shadow of recurrence" (#7) (Table 2). Despite surgeons discussing BCT and UM as equivalent treatment options for long-term survival, participants voiced their beliefs that if all the breast tissue was removed then the 'cancer couldn't come back' and they would, in turn, survive. "By being aggressive with the treatment, I'm facilitating survival" (#22) (Table 2).
Some women also chose UM to avoid RT. Those concerned about the effects of radiation had previous experiences with loved ones who had undergone RT. "I saw side effects. My decision was if I ever… need

TABLE 2 Concepts and supporting quotes

Concept 1: Diagnosis	"I was sure that my body was rampaged by cancer. Not only was I in panic mode about the decision about which surgery to have, I was also in panic mode of, if I have the surgery was I still going to have cancer"(2)*
	"I was completely shocked because I expected everything to be fine." (15)
	"You just hear the word 'cancer'. And you just think, 'Oh, my God. I can't believe this is happening to me." (18)
Concept 2: Discussion of treatment options	"She just described both procedures and asked me which I would prefer. Some women may have a lumpectomy and some have a mastectomy." (20)
	"She told me that I could have the lumpectomy or mastectomy, but I preferred mastectomy. The chance of survival for a lumpectomy or mastectomy, there's no – they're almost the same. There's no difference." (3)
Equivalent survival	"Everything that I had read was that people who chose radical mastectomies, they don't really need it. That's what the research at the time said, that you can choose lumpectomy and radiation and it would be the same as basically a mastectomy." (17)
Advantages and disadvantages	"I just remember she drew me the diagram she showed me (how she could remove the lump by using lumpectomy). I knew that this was a good recommendation because you can preserve the breast, right? This is very important because this is part of the body." (7)
	"I had the option for a lumpectomy – but if I had a lumpectomy, I would have to have radiation to reduce the risk of it coming back. If I have a mastectomy, I wouldn't need radiation after. You can't do reconstruction with just an implant on a radiated breast typically, if I had a lumpectomy, I wouldn't be able to have reconstruction. Then even with a lumpectomy, she talked about chemo." (13)
Adjuvant treatment	"I know if you do mastectomy, then there's still a good chance that you have to do chemotherapy but very unlikely that you have to do radiation. But if you do lumpectomy, there's a good chance that you have to do both (chemotherapy and radiation). I think for lumpectomy it's almost a must to do radiation." (7)
	"Avoiding the radiation was important but here was also possibility of chemo. Well, I chose the mastectomy so I didn't have to do radiation. When it came time to decide whether I have to do chemo, apparently there was this new test that helps you decide whether you can/have to take chemo or not." (10)
Patient-initiated discussion of CPM	"Dr. B actually suggested that, you know, I shouldn't have it removed (CPM). I brought it up." (6)
	"Dr. C was very professional and very a matter-of-fact and very much 'here is what we recommend. These are your choices (lumpectomy and unilateral mastectomy)'. I was out of the gate in that meeting. I said, 'I'm already leaning towards having a double mastectomy'." (9)
	"I asked to arrange the mastectomy, and when I was talking to the surgeon I said I'd really like to go and do both." (13)
Surgeons discouraged CPM	"She really cautioned me against it; didn't want me to do that at all. She said 'often women have this as a first reaction but it's not going to change the outcome. It's not going to extend your life'." (13)
	"I asked to arrange the mastectomy, and when I was talking to the surgeon I said I'd really like to go and do both. He said, 'That's a lot of surgery'. I felt like he was, you know, discouraging me." (14)
Concept 3: Sources of information	"I got information from (surgeon) and from the booklets. I searched the Internet but it didn't tell me more than I already knew from the information that I got from my physician and my surgeon and the booklets." (3)
Healthcare team	"She (surgeon) drew a little diagram, where I stand on the sides of how bad it is; and pamphlets of course." (13)
Experiences with friends and family	"I had two friends die within a year previous from breast cancer. One had suffered with it for fifteen years and the other was ten. They both said to me, 'I wish I had just taken them off'." (26)
	"My aunt, she had a lumpectomy originally and the cancer came back. That's when she decided to have the mastectomy. So, she was just like, 'Just do it'." (25)
	"Watching my mother die was really hard, incredibly hard. She was diagnosed in one year and exactly one year of the day of her diagnosis, she died. So it was fast, and I was the primary care giver, so it was very hard. I had been exposed to cancer, first-hand. My mother died in my arms." (2)
Other breast cancer patients	"A local support group, and they actually referred me to talk to some of the patients. There is one particular patient and she was very helpful. She was telling me about all her (breast cancer) experiences." (6)
	"One of the women I made very close friends with. She basically had gone through a mastectomy, before I did. She knew what it was all about and she was going in for her second one. She needed to have another mastectomy. Because I wasn't familiar with any of this, she was actually my mentor. I don't want to wake up every day and say, "Did it go over there?" (8)

TABLE 2 continued

Concept 4: Recurrence, contralateral breast cancer, and survival rates	"I'm just thinking if there's breast tissue left there it's coming back." (1)
	"I'm not worried about my survival from this (treated side) – I'm worried about the other side." (3)
	"He was very clear to me to say that when the cancer is in the breast and it's dealt with, it's considered that it's cured. I mean, he was using numbers for me, like 97–100 % cure rate. By having the mastectomy, I would be removing not only the tumor, but hopefully a whole whack of rogue cells that might be still in the breast." (15)
	"Just because there are survival numbers, doesn't mean that is going to dictate my future. I figured that you know, by being aggressive with the treatment, I'm facilitating that." (22)
	"Take these two breasts off. I would be willing to take that risk so that I didn't die from breast cancer at the age of 63." (18)
Concept 5: Reasons for choosing Unilateral Mastectomy	"I made up my mind to do the mastectomy because I don't want to live in the shadow of recurrence. I wanted to deal with it aggressively. I just wanted to kill it." (7)
	"I preferred a lumpectomy because of the changes in the shape of my body but I was afraid of recurrence. I decided to have a mastectomy because the most important factor for decision making about mastectomy, was that of recurrence." (3)
	I didn't want to risk just taking out one or two spots and then having to come back and deal with another surgery, and then six months it comes back. I didn't want to be living with the situation where I had to constantly worry what's left, and where and when it's going to come back … what was more important is the fact that I didn't want to deal with – have this constant cloud over my head so I took the drastic (the more drastic) measure." (10)
	"I saw side effects; my friend died from breast cancer years ago. My decision was if I ever get any disease that needs radiation, I will not do it." (23)
	"25–30 doses of radiation over my left side which is my heart, it doesn't really appeal to me." (18)
Concept 6: Reasons for choosing Contralateral Prophylactic Mastectomy	"In my mind cutting it out was getting rid of it. I had convinced myself I was going to remove the breast and then I decided I was going to do the whole thing (and remove them both)." (25)
	"Nobody is a 75 % (survival). Nobody is a 90 % (survival). Everybody is a zero or a one… I'd rather be a zero. For me, peace of mind, is the number one thing. The only way for me to have peace of mind is to not have it (contralateral breast)." (14)
	"I'm looking for 45 years, not five. I don't want five years. I'd like to see my son who was three, turn fifty. So, I really am looking for more like 45 or 50, you know?" (9)
	"I need to have it look symmetrical versus saving a breast for whatever have you. I knew that long-term I'd worry about cancer getting into my other breast." (19)
	"My choice would be flat, because that also gives me the peace of mind as well as the matching symmetry." (14)
Concept 7: Postoperative outcomes	"I want to be comfortable in my skin, feel like a woman again, feel completely whole again" (9)
	"I'm really very ashamed – I don't want my husband to see me. I never show him my scars on my breasts." (11)
	"I just wanted everything to be as normal as normal could be. With the clothes on, fine, you know? But nobody sees at the end of the day when you take off your mask." (12)
	"Why can't I live with the pain; the nerve is what's burning." (23)
	"Nobody explains to you what it is going to look like. Nobody explains to you the effect of scar tissue on the body. I'm in constant pain from the scar tissue." (17)
Overall Theme: Taking control of cancer	"Dr. C gave me choices. But I decided what was good for me … I had the double mastectomy." (8)
	"You control it. You spend the rest of your life controlling it; hoping it doesn't resurface. You have to take charge of it." (16)
	"I finally was in control. I didn't give a care if God said, 'You're going to have this'. I'm going to make the decision, you see because I was in control now." (18)
	"I didn't want somebody to just tell me, 'You're going to have it'. I want to be in control, you know? I have to be in control of what happens to me."(21)

* Patient participant study number

radiation, I will not do it. (#23)" (Table 2). Concerns around RT were always secondary to the worry around cancer recurrence.

2. *Choosing CPM* Patients choosing CPM also voiced their fear around developing CBC; "… wake up every morning and think, 'Oh, did it go there (other side) yet?" (#8). This fear prevailed despite discussions with the surgeons around the low risk of developing CBC. Participants felt that by undergoing UM + CPM they would ensure they 'never have to go through this again' and, in turn, have a much longer survival: "I'm looking for 45 years, not five" (#9) (Table 2).
Some participants who had initially chosen to undergo UM for their index cancer, ultimately underwent UM + CPM for symmetry. Women were informed that symmetry would be better achieved if both breasts were reconstructed rather than trying to 'match' the reconstruction to the natural breast. "My choice would be flat, because that also gives me the peace of mind as well as the matching symmetry" (#14) (Table 2). Concerns around symmetry were secondary to the fear of CBC.

Postoperative Outcomes Only one patient questioned her decision for more extensive surgery, yet, upon further exploration, the majority of our patients did express either ongoing physical or psychological concerns. These concerns were predominately around body image and cosmesis: "I want to feel like a woman again, feel completely whole again" (#9) (Table 2). A minority of our patients had chronic postoperative pain, from both nerve and scar tissue: "Why can't I live with the pain; the nerve is what's burning" (#23) (Table 2).

'Taking Control of Cancer' 'Taking control of cancer' is the dominant theme that emerged throughout the entire discussion. While women participated in the surgical consultation and turned to family and friends as sources of information, the final decision was made by our participants alone. Patients perceived that UM would definitively prevent ipsilateral recurrence and CPM would ensure prevention of CBC; in turn, this translated into the belief of guaranteed long-term survival. In our women, more surgery was seen as exerting greater control over their cancer. "You control it… You have to take charge of it" (#16).

DISCUSSION

This is the first study to describe why women are choosing UM ± CPM for the treatment of ESBC in an in-depth fashion. We determined the decision to undergo mastectomy is a response to fear and anxiety; by choosing more extensive surgery, women are attempting to control their cancer outcomes. Recent surveys conducted by Rosenberg et al.[35] and Hawley et al.[25] demonstrated that women choose CPM due to fear of recurrence; our study expands on these findings. Understanding how fear shapes women's decision to undergo UM ± CPM will facilitate informed decision making by enabling improved discussions around surgical care between healthcare providers and patients.

A previous cancer experience with family and friends heightened our patients' fear, and played a notable role in our patients' decision making. The literature has demonstrated that a previous cancer experience within the family produces feelings of vulnerability within family members, and shapes their cancer knowledge.[36] In hereditary breast cancer counselling, cancer risk and decision making are interpreted through the experience of affected family members, rather than statistical probabilities.[37] Similarly, a diagnosis of BRCA generates a 'shared identity' between those newly diagnosed and previously affected loved ones.[38] We found this 'shared identity' among our patients resulted in women placing more emphasis on experiential knowledge than objective risk assessment.

The experiential knowledge shared by our patients was predominately negative as patients recalled suffering and loss of affected family and friends. Similarly, patients who received information through networking with other patients recounted stories of recurrence and metastasis, in-turn regretting the choice for BCT. In keeping with previous literature, we found that despite the surgeons describing equivalent survival of the surgical options, subjective risk perception superseded objective information.[39–41] Rosenberg et al. demonstrated that despite being aware that CPM did not offer a survival benefit, women who underwent CPM over-estimated their risk of recurrence and chose CPM to 'avoid recurrence and extend their life'.[35] Similarly, our patients felt that they were at very high risk of local recurrence, the development of CBC, and their likelihood of disease-related death. Our patients' response to this misperception was to choose UM ± CPM as they believed that survival would be different for them. By choosing to have more extensive surgery, our patients insisted that they had definitively increased their likelihood of living longer.

The perceived ability to control illness and regulate emotional response in a threatening situation has been previously described in cognitive literature.[42–44] 'Mastery' has been defined as the extent to which an individual perceives their outcomes as being under their control.[45] Similarly, 'exaggerated control beliefs' are those where an individual attempts to control a situation where the outcome is unchangeable.[46] It has been demonstrated that patients using mastery and exaggerated control as coping

strategies are at higher risk of psychosocial morbidity, should disease recur.[47] All of our patients chose mastectomy as they wanted to ensure this would 'never happen to them again', demonstrating exaggerated control beliefs; in the setting of disease progression (an outcome not controllable through mastectomy), our patients may be at risk for a heightened deleterious psychological response.

In women who are not at high-risk for CBC, there are no guidelines that recommend CPM; a recent Cochrane update recommends against the use of CPM in non-high-risk women as there is no demonstrated survival benefit.[48] While CPM reduces the risk of CBC, this risk is already low in ESBC, with an estimated rate of 0.5 % per year (lower in women undergoing adjuvant therapy).[49–51] Rosen et al. demonstrated that the vast majority of breast cancer deaths in women with ESBC were due to systemic spread of the index cancer rather than the development of a CBC and subsequent death.[52] However, undergoing CPM doubles the risk of potential complications associated with UM;[53,54] major complications, including infection, necrosis, bleeding, and reoperation, occur in up to 16 % of patients after mastectomy of the non-cancerous breast.[54,55] Long-term complications such as sensory skin disturbances and chronic pain have been reported by up to 50 % of mastectomy patients and these may impact long-term quality of life.[56–58] The literature has demonstrated that while 85 % of patients report overall satisfaction with CPM, qualitative assessment demonstrates up to 84 % of those who report overall satisfaction experience some dissatisfaction in the areas of body image, sexuality, and chronic pain on the non-cancerous side.[59,60] Many of our patients initially appeared content with their decision for more extensive surgery; however, on further exploration, most participants shared concerns around body image, skin sensation, and, occasionally, chronic pain.

With no evidence of medical benefit, and the potential for complications, comes an inherent tension between the patient's request for CPM and the surgeon's obligation to practice evidence-based medicine. This tension was reflected in our study as patients had to negotiate their request for CPM. As the benefits of undergoing CPM in non-high-risk patients are minimal, we suggest additional strategies, such as decision aids, to increase patient knowledge about the risks of recurrence, CBC, and the net benefit of CPM. While current decision aids do not include information about CPM, they have been demonstrated to improve patient knowledge around BCT and UM.[61] Decision aids that incorporate both positive and negative patient narratives may alter patients' understanding of both the risks and benefits of treatment options;[62–64] such tools could therefore be useful for women choosing CPM. Given the potential for long-term complications, patients making the choice to undergo more extensive surgery need to be accurately informed about the risks associated with ESBC and the net benefits of UM ± CPM; this choice should not be based solely on the belief that more surgery equates to better survival. As demonstrated in the study by D'Agincourt-Canning, understanding how experiential knowledge shapes decision making, and discussing patient's previously lived experience, can permit healthcare providers to address the information that is most influential during the consultation process.[38] Ensuring surgeons have an understanding about the role of fear and experiential knowledge in shaping a patient's choice for mastectomy, coupled with educational tools, may help inform the patient's decision-making process.

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