

Social Network, Surgeon, and Media Influence on the Decision to Undergo Contralateral Prophylactic Mastectomy

Maria K. Venetis, PhD,* Erina L. MacGeorge, PhD,† Dadrie F. Baptiste, MD,‡
 Ashton Mouton, MA,* Lorin B. Friley, MA,* Rebekah Pastor, MA,*
 Kristen Hatten, PhD,* Janaka Lagoo, MD,‡ Monet W. Bowling, MD,‡
 and Susan E. Clare, MD, PhD§

Objectives: The rate of contralateral prophylactic mastectomy (CPM) has risen sharply in the past decade. The current study was designed to examine social network, surgeon, and media influence on patients' CPM decision-making, examining not only who influenced the decision, and to what extent, but also the type of influence exerted.

Methods: Patients (N=113) who underwent CPM at 4 Indiana University-affiliated hospitals between 2008 and 2012 completed structured telephone interviews in 2013. Questions addressed the influence and influence of the social network (family, friends, and nonsurgeon health professionals), surgeon, and media on the CPM decision.

Results: Spouses, children, family, friends, and health professionals were reported as exerting a meaningful degree of influence on patients' decisions, largely in ways that were positive or neutral toward CPM. Most surgeons were regarded as providing options rather than encouraging or discouraging CPM. Media influence was present, but limited.

Conclusions: Patients who choose CPM do so with influence and support from members of their social networks. Reversing the increasing choice of CPM will require educating these influential others, which can be accomplished by encouraging patients to include

them in clinical consultations, and by providing patients with educational materials that can be shared with their social networks. Surgeons need to be perceived as having an opinion, specifically that CPM should be reserved for those patients for whom it is medically indicated.

Key Words: breast cancer, decision-making, prophylactic, social networks

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The rate of contralateral prophylactic mastectomy (CPM) has risen sharply in the past decade.^{1–4} This increase has been associated with a number of factors including patients' perception that CPM improves survival (vs. unilateral mastectomy).⁵ However, there has been no survival benefit from CPM demonstrated in the absence of specific risk factors (eg, a BRCA1/2 mutation),^{6–9} and the procedure is both more costly than unilateral mastectomy¹⁰ and is associated with significant increases in a subset of surgical site complications.¹¹ Consequently, expert medical recommendations, such as those from the National Comprehensive Cancer Network, advise that women with unilateral breast cancer should not undergo CPM in the absence of factors that strongly increase breast cancer risk (http://www.nccn.org/professionals/physician_gls/PDF/breast.pdf, https://www.nccn.org/professionals/physician_gls/pdf/breast_risk.pdf).

Indeed, research on predictors of CPM indicates that the decade's increase is patient driven rather than surgeon driven.^{12–14} Large-scale studies of demographic factors demonstrate that women are more likely to undergo CPM if they are younger, more affluent, well insured, and white.^{15,16} Taken together, these factors suggest a profile of CPM patients who have the resources and competencies to successfully advocate for procedures their physicians do not necessarily support. In addition, a recent study found a 3-fold increase in CPM when patients reported a “patient-driven decision” versus a “physician-driven decision.”⁵

However, women with breast cancer are also wives, mothers, daughters, sisters, and friends, and as such, their decisions about breast cancer treatments are made in the context of these relationships.¹⁷ Breast cancer patients often bring spouses, friends, or children with them to medical visits¹⁸ and depend on them for multiple forms of support,¹⁹ which can include participation in decision-making.^{17,20} Women with breast cancer also utilize traditional mass media, the Internet, and social media, where they have a high likelihood of encountering information about breast cancer, ranging from science news reports to stories about celebrities with breast cancer.^{21–24}

From the *Brian Lamb School of Communication, Purdue University, West Lafayette; ‡Department of Surgery, Indiana University School of Medicine, Indianapolis, IN; †Department of Communication Arts and Sciences, Pennsylvania State University, University Park, PA; and §Department of Surgery, Feinberg School of Medicine, Northwestern University, Chicago, IL.

Present address: L. Brooke Friley, MA, Department of Communication and Media, Texas A&M—Corpus Christi, 6300 Ocean Dr, Corpus Christi, TX 78412.

Present address: Rebekah Pastor, MA, CoreClarity, P.O. Box 863692, Plano, TX 75086.

Present address: Kristen Hatten, PhD, School of Communication, Western Michigan University, 1903 W Michigan Ave., Kalamazoo, MI 49008

Present address: Janaka Lagoo, MD, Ariadne Labs, 401 Park Drive, Boston, MA 02215.

Present address: Monet W. Bowling, MD, Hendricks Regional Health, 1000 East Main Street, Danville, IN 46122.

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Reprints: Susan E. Clare, MD, PhD, Department of Surgery, Feinberg School of Medicine, Northwestern University, 303 E. Superior Street, Lurie 4-113, Chicago, IL 60611. E-mail: susan.clare@northwestern.edu.

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To the extent that social network members and mass media are significant influences on patient demand for CPM, the medical community will need to address these influences if the existing trend is to be halted and reversed. To date, several authors have asserted that social network members affect patients' CPM choices,²⁴ but there has been little systematic attention to this influence. In perhaps the only study to date that has assessed social network influence on CPM decisions, Soran et al²⁵ reported that 49% of the women in their study were influenced by spouses or partners, 30% by friends and relatives, and 25% by their mothers. Women in their study also reported that 68% of spouses/partners were positive toward CPM, as were 64% of friends and relatives. The current study was designed to provide a more detailed analysis of social network influence on CPM decision-making, examining not only who influenced the decision-making, and to what extent, but also the type of influence exerted.

MATERIALS AND METHODS

Ethics

This study was approved by the Indiana University Institutional Review Board (IRB-04, protocol number 1210009689; and IRB-03, protocol number 1304011094). All research was carried out in compliance with the Helsinki Declaration.

Participants

Potential participants were identified from the Indiana University, Wishard (now the Sidney and Lois Eskenazi Hospital), IU Health North and IU Health West hospital billing records using the procedure code for bilateral mastectomy during the years 2008 to 2012. The lists were then curated to identify patients who had undergone CPM (n=326). The patient's name, address, telephone number, and hospital location were obtained from the medical health record system. These patients were mailed an introductory letter and study information sheet, after which they were contacted by telephone and a structured interview conducted with those who agreed (n=117). Only 16 patients contacted were recorded as explicitly refusing the interview; no reasons were provided, and information about these patients was not retained. Non-participation of all others resulted from inability to reach patients at the phone numbers in their records. Data were collected in the summer and fall of 2013, so there was some overlap between the period of data collection and media attention given to Angelina Jolie's prophylactic double mastectomy (<http://www.nytimes.com/2013/05/14/opinion/my-medical-choice.html>). However, all the surgical decisions were made before 2013.

All participants were women (n=117, 100%); 4 patients self-identified as BRCA positive, and their data were removed from analysis because this suggests that CPM was medically indicated, changing the nature of the surgical decision-making process. Participant demographics (n=113) reflect participant status at the time of the surgery. Participants were aged 22 to 73 ($M=50.29$, $SD=12.50$), predominately married (n=86, 77%), employed (n=73, 66%), and had private insurance (n=80, 71%). Participants identified as white (n=99, 88%), black (n=12, 11%), and Hispanic (n=2, 1.8%). Participants varied by household income: <25K (n=7, 6.20%), 26 to 50K (n=20, 17.7%), 51 to 75K (n=25, 22.1%), 76 to 100K (n=17, 15%), and >101K (n=30, 10.6%). Participants reported various degrees of education: high school or less (n=22, 19.5%), some college (n=36, 31.9%), bachelor's degree (n=32,

28.3%), and graduate education (n=21, 18.6%). Most women reported diagnoses of invasive ductal cancer (n=31, 26.5%), ductal carcinoma in situ (n=24, 20.5%), invasive cancer (n=27, 23.1%), and invasive lobular cancer (n=9, 7.7%). Most were diagnosed in 2008 to 2012. Four participants with diagnosis dates before 2008 reported having had CPM after a local recurrence.

Protocol

This analysis was part of a larger investigation of how breast cancer patients select CPM. Participants initially responded to items reporting their individual motivations for undergoing CPM; analyses of these data are reported elsewhere (Baptiste DF, MacGeorge EL, Venetis MK, Mouton A, Friley LB, Pastor R, Hatten K, Lagoo J, Clare SE, and Bowling MW. 2016; submitted for publication). Then, participants were asked to identify everyone with whom they had talked about what kind of surgery to have, including both social network members and health care providers other than surgeons. For each member of the social network, participants provided the relationship to the other (ie, friend, mother, husband), the other's history with breast cancer (with or without history of breast cancer), the degree of influence ranging from 0 (no influence) to 5 (great deal of influence), and a free-response description of the type of influence exerted. For each health care provider, participants provided the type of relationship (eg, nurse practitioner, counselor), degree of influence, and free-response description of influence. Participants were then asked to describe the discussion they had with the surgeon about the surgical decision, followed by 2 closed-ended questions about whether the surgeon suggested CPM and supported CPM. Finally, participants were asked whether the media had played role in their decisions, and if so, to describe that influence. The interview concluded with questions about race, education, employment, income, and insurance.

On the basis of review of the data, 2 of the authors (E.L.M. and M.K.V.) created coding categories for the types of influence exerted by social network members and nonsurgeon health care professionals. Definitions and examples are provided in Table 1. Similarly, coding categories were created for the types of influence exerted by surgeons (Table 2). These authors individually coded the data. Coding reliability between authors was good (Krippendorff $\alpha=0.77$ for the 8 types of network influence and 0.84 for the 4 types of surgeon influence). Discrepancies were resolved through discussion.

RESULTS

As shown in Table 3, nearly all participants reported discussing their surgical options with at least 1 person other than a surgeon; only 3 reported not talking with anyone. Many reported talking with male spouses or partners, 1 or more friends or family members who had experienced breast cancer, and 1 or more friends or family members who had not experienced breast cancer. Smaller percentages reported talking with health professionals, such as a medical oncologist, nurse, therapist, or member of the clergy, and with children. Median and modal values indicate that the "typical" participant talked with 2 or 3 people about the surgical decision.

Also as shown in Table 3, most participants also reported that at least one of the individuals they talked with influenced the decision to some degree. Participants most frequently reported as "influencers" their spouses, family, and friends with a history of breast cancer, followed by health

TABLE 1. Types of Influence

Type of Influence	Definition	Example
Experiential	Other had direct or indirect experience with breast cancer that participant reported as influence	Friend 1: had DCIS and underwent lumpectomy and radiation. With her anything that could happen with the radiation happened, and her cancer has come back. I asked her about whether I should do the double and she cried and said she wished she had done that too
Talk	Other engaged in conversation, listened, and shared thoughts	Sister: There to process the information, like a sounding board. She came to the doctor's office with me for my appointments
Encouraged CPM	Other actively promoted CPM	Children: Entire immediate family (kids and husband) wanted me to do double mastectomy, had big fear of it coming back, so I thought it was the best decision. Made sure everyone got their feelings out, we talked it over as a family
Supported my choice	Other was agreeable with decision made by participant	Sisters: they were on board for whatever I wanted to do
Decided together	Other discussed treatment options and made the treatment with participant (different from <i>talk</i> in emphasis on joint decision-making)	Husband: I really value his opinion, we discussed everything and decided together
Was supportive	Other was supportive (no further detail about influence)	Friend: She was just as supportive as my mom and dad. She took me on like I was her daughter. She took me back and forth to my appointments, she went with me to my treatments, to my appointments with my surgeon. She was very supportive and said she would do whatever she had to do to see me through my surgery
Provided information	Other helped participant to find or understand information	Nurse: explained her diagnosis in layman's terms. Talked to her extensively about the pros and cons of her decisions
Discouraged CPM	Other supported alternative surgical options	Friend 3: Had breast cancer and underwent single mastectomy. She just thinks her way is the best way so she was very supportive but not very helpful. So she was ok with my choice, she had the same cancer surgeon, but she doesn't understand why anybody would do anything different from what she does about her cancer and she can't let people make their own decisions

professionals, family, and friends without experience of breast cancer, and children. As indicated by the median and modal values, the "typical" participant's decision was influenced by 2 people.

On average, spouses, children, family, friends, and health professionals exerted a meaningful degree of influence, with a mean of 3.2 (SD = 1.25) on a scale where 3 corresponds with "some influence." The greatest average influence was reported from spouses/partners (M = 3.67, SD = 1.36) and children (M = 3.65, SD = 1.32), followed by family and friends without a history of breast cancer (M = 3.48, SD = 1.45), family and friends with a history of breast cancer (M = 3.43, SD = 1.37), and nonsurgeon health professionals (M = 2.95, SD = 1.41). However, paired-samples *t* tests revealed that these mean differences were not significant; *P*-values for all tests exceeded 0.05, indicating that the quantity of influence exerted by individuals in these groups is not statistically different.

As shown in Table 4, there was variation in the type of influence exerted by members of the social network. A 1-way χ^2 test indicates that this variation is significant ($\chi^2 = 106.66$, $P < 0.001$). The most common type of influence was experiential, in which a social network member had direct or indirect experience with breast cancer that the participant reported as influence. Although the details reported were diverse, most responses in this category focused on cancer recurrence after lumpectomy or a new contralateral primary after a single mastectomy, family history of cancer, or (less commonly) on satisfaction with CPM. Consequently, the experiential form of influence consists largely of implicit support for CPM (from the patient's perspective). Moderately (and similarly) frequent forms of influence were (in order of frequency) supporting the patient's choice, providing information, encouraging CPM (explicitly), being generally supportive, and allowing the

patient to talk about the decision. Deciding together and discouraging CPM were infrequent.

TABLE 2. Surgeon Influence in Discussion of Surgery

Type of Surgeon Influence	Example	Frequency
Presented options	The surgeon was pretty thorough in going through different treatment options and the pros and cons	74
Encouraged CPM	She highly suggested that I have both of them removed because I had it for 2 years and it was undetectable. If I didn't it could come back and I may not know it. It was such a high risk that I should remove them	8
Discouraged CPM	...She told me to think about it, consider it over a short time, and if that's what I decided I wanted she would do it even though that's not what she would personally recommend...	3
Other	So happy I found her! She explained everything really well. She didn't rush me. I thought she was a little sentimental, sometimes a little too much, but she's very nice and not abrasive. She's good at what she does, and it shows when she interacts with her patients	23
Total		108*

*Five participants did not respond to this question, or were unable to recall details of discussion with their surgeon.

TABLE 3. People Talked With and Influenced by

	No. Participants Who Talked With Person of This Type (n [%])	No. People They Talked With	No. Participants Influenced by Person of This Type (n [%])	No. People They Were Influenced by
Spouse/partner	75 (66.4)	N/A	58 (48.7)	N/A
Children	43 (38.1)	Range: 1-2* M=1.16, SD=0.37 Median=1, mode=1	17 (15)	Range: 1-2* M=1.41, SD=0.51 Median=1, mode=1
Friends/family—breast cancer†	85 (75)	Range: 1-8 M=3.40, SD=2.82 Median=2, mode=1	57 (50.4)	Range: 1-5 M=1.84, SD=1.05 Median=1, mode=1
Friends/family—no breast cancer	65 (57.5)	Range: 1-6 M=2.92, SD=2.20 Median=2, mode=1	30 (26.5)	Range: 1-2 M=1.13, SD=0.35 Median=1, mode=1
Health professionals	42 (37)	Range: 1-7 M=4.19, SD=2.88 Median=5, mode=7	36 (31.8)	Range: 1-3 M=1.25, SD=0.50 Median=1, mode=1
Any	110 (96.5)	Range: 1-23* M=6.9, SD=7.93 Median=3, mode=2	99 (87.6)	Range: 1-8* M=2.7, SD=1.67 Median=2, mode=2

*Values reported in this cell may slightly underestimate of children talked with or influencing decision, as some interviewers did not clarify whether participants who said “children” were talking about 2 children or more.

†One female domestic partner was included in the friends/family with breast cancer because she was a breast cancer survivor.

Different influence strategies were also more and less frequent in different types of relationships. Discouraging CPM and deciding together occurred too infrequently to be included in a 2-way χ^2 analysis (they resulted in multiple cells with very low expected frequencies). The number of influence attempts reported from children was also too small to be treated as a separate category, so influence by children was combined with spouse/partner, as these relationships were both in the participant’s nuclear family and their reported quantity of influence was highly similar. The 2-way χ^2 assessing the frequency of the 6 most frequent influence types in the 4 relationship types indicated that the observed variation is significant ($\chi^2_{15}=233.04$, Cramer $V=0.557$, $P<0.001$). As shown in Table 4, family and friends who had experienced breast cancer were most frequently reported to exert experiential influence, whereas health professionals typically provided information. Spouses, children, and family or friends who had not experienced breast cancer tended to use the remaining influence types: talking, encouraging CPM, supporting the patient’s choice, and being generally supportive.

As shown in Table 2, most participants described the surgeon’s behavior during the discussion of surgery as providing options. Relatively few were reported to explicitly encourage or discourage CPM. A 1-way χ^2 test indicates that this variation is statistically significant ($\chi^2_3=117.11$, $P<0.001$). However, somewhat more than half (N=62, 54.9%) of participants reported that their surgeons suggested CPM, whereas somewhat less than half (N=49, 43.4%) said their surgeons did not (2 participants did not answer this question). Only 1 participant reported that the surgeon did not support her choice of CPM; aside from the 2 who did not answer, all other participants believed their surgeons supported their choice.

A minority of participants (N=31, 27.4%) reported some degree of media influence on the decision to elect CPM. Sources of reported influence included television (n=12), Internet (n=11), radio (n=2), and books (n=6). Some participants mentioned specific celebrities and authors such as Christina Applegate, Suzanne Summers, Susan Love, and Dianna Duberry (an Indianapolis news anchor). Others

TABLE 4. Frequency of Influence Types in Different Relationships

Type of Influence	Spouse	Children	Spouse and Children	Family/Friends With Breast Cancer	Family/Friends: No Breast Cancer	Health Professionals	Total
Experiential	0	0	0	70	4	2	76
Talk	8	2	10	8	9	2	29
Encouraged CPM	12	5	17	7	10	0	34
Supported my choice	17	3	20	7	12	3	42
Was supportive	12	4	16	3	7	6	32
Provided information	0	0	0	4	7	26	37
Decided together	6	0	6	0	1	0	7
Discouraged CPM	0	2	2	1	1	0	4
Total	55	16	67	100	51	39	255

Boldface values were included in the reported 2-way χ^2 analysis.

mentioned a range of stories focused on breast cancer topics, including mammograms, diagnosis, mortality, mastectomy, and breast reconstruction.

DISCUSSION

Prior research on CPM decisions suggests that the increase in this procedure is patient driven rather than physician driven.¹²⁻¹⁴ The current study provides additional perspective on this phenomenon, contributing evidence that women who chose to pursue CPM elect this surgery, at least in part, with influence and support from members of their social networks, including spouses, children, other family, friends, as well as nonsurgeon health care professionals. Surgeons are regarded as neutral providers of options, and media influence is present, but limited.

Most women in this study talked to multiple social network members about their CPM decision, and reported some degree of influence from those others. Observed differences in the degree of influence between different relational categories did not achieve statistical significance, though this may be a function of sample size. The current data suggest that surgeons need to anticipate the possibility of meaningful influence on their patients' decisions from others who inhabit a variety of relational roles, ranging from spouses and children to therapists and clergy. These findings suggest a strategy of actively involving these individuals in the information sharing and educational portion of the clinic visit. In their commentary on overtreatment in breast cancer, Katz and Morrow²⁶ state that the outcomes of the various treatment options being considered in the examination room must be clarified. Both they and Angelos et al¹³ point out that heuristics (gut reactions) and counterfactual thinking drive patient desire for more extensive treatment. With patients' consent, spouses, partners, and children should be encouraged to attend the discussion of treatment options. They should be actively engaged in the conversation and given the opportunity to ask questions, and ideally transformed from implicit or explicit supporters of CPM (almost 20% in our sample) to providers of accurate information about the utility of the procedure. During their subsequent interactions with the patient, the information these individuals glean from the clinical encounter may help them counter the patient's gut reactions and anticipated regret.

Efforts to educate members of breast cancer patients' social networks need not be confined to the examination room. The Pew Research Center's Internet Project determined as of January 2014 that a majority of US adults use social networking sites such as Facebook. Percentages were 49% for age 65+, 65% for ages 50 to 64, 82% for ages 30 to 49, and 89% for ages 18 to 29 (<http://www.pewinternet.org/fact-sheets/social-networking-fact-sheet/>). This suggests another strategy to combat unindicated CPM. Material should be developed that provide data on the likelihood of a metachronous contralateral breast cancer, survival as a function of the known cancer, complications, cost of CPM, and long-term satisfaction/dissatisfaction of patients who have undergone reconstruction. This material should be written to address low levels of health and scientific literacy and be presented in a visually appealing electronic format. This would provide patients with an opportunity to share evidence-based information with those they will be consulting with regarding CPM; it would be ideal if this information were shared across the patients' social networks so as to reach and inform much larger audiences than those accessible through clinical interactions.

The most frequent type of reported influence was experiential, or being influenced by another person's experience. This type of influence was exerted principally by friends and family who had gone through breast cancer, and consisted largely of reports of cancer recurrence or a new primary breast cancer, and family history of breast cancer. Thus, although coded separately from explicit encouragement of CPM, participants clearly regarded this type of influence as implicit support for the CPM choice. Although it is not surprising that patients sought out family and friends who had gone through breast cancer and had contemplated similar treatment decisions, the fact that their experiences supported the choice of CPM should give us pause. Data suggest that regret regarding treatment decisions for localized breast cancer is low and relatively stable over time for most patients.^{27,28} Most friends and family members diagnosed with breast cancer would have been treated by breast conservation, and a lesser number by unilateral mastectomy.²⁹ Given that regret regarding treatment decisions is low, we would have expected that these individuals would have voiced satisfaction with their treatment decisions. They may have done so but that is not the message our respondents heard. Local recurrence is a relatively infrequent occurrence,^{30,31} but the report of this event by the friend or family member or perhaps an anecdotal report of local recurrence in someone the friend/family member is acquainted with seems to have been determinative. This underscores the challenge of combating powerful individual narratives with aggregate statistical data.³² Further research is needed to determine how to accomplish this goal in the context of breast cancer treatment decisions.

Whereas most of our participants reported social network influence on their decisions, mass media influence was reported by a minority. This influence stemmed principally from television or Internet sources; some participants mentioned specific celebrities. Because the CPM decisions reported in this study took place before the publicity surrounding Angelina Jolie and Sandra Lee's "double mastectomies," we may have underestimated the current potential for media influence on CPM decisions. However, the data to date indicates that the "Jolie Effect" has been mainly to increase the number of women seeking genetic counseling/*BRCA* testing.^{33,34} In all likelihood, the more powerful influence is now taking place through *social* media, where patients who post about themselves or others choosing CPM combine the impact of personal endorsement with broad reach into their own social networks and beyond. This too speaks to the value of developing accurate and attractive educational materials that are easy to share electronically.

In free-response descriptions of the surgical consultation, participants reported few surgeons as either overtly favoring or opposing CPM, but instead described them as providing options. Analyzing the ethics of surgeon involvement in the CPM decision, Angelos et al¹³ have framed the challenge facing surgeons as one of respecting patient autonomy versus abdication of responsibility to avoid doing harm. If the recollections of our respondents are accurate, the surgeons presented themselves as having no strong opinion for or against CPM. Although more than half of respondents also reported that their surgeon "suggested" CPM, it has to be assumed that this was in the context of listing the treatment options. It is also unsurprising that participants overwhelmingly reported "support" for the CPM decision, as few surgeons would continue expressing lack of support once they had agreed to perform CPM. Collectively, these findings suggest that surgeons need to be more assertive in conveying their perspective.

As Katz and Morrow²⁶ point out, the responsibility for minimizing overtreatment in breast cancer rests largely in the hands of the physician. The National Accreditation Program for Breast Centers 2014 Edition of the Standards Manual states that centers are compliant when they utilize evidence-based breast cancer management guidelines such as those of the NCCN (<https://www.facs.org/media/files/quality%20programs/napbc/2014%20napbc%20standards%20manual.ashx>). The NCCN guidelines clearly discourage CPM unless the patient is 35 years and below or premenopausal and carrier of a known *BRCA1/2* mutation (http://www.nccn.org/professionals/physician_gls/PDF/breast.pdf). Therefore, it is essential that surgeons are perceived to have an opinion, which is to limit CPM to where it is appropriate, and that they can clearly articulate the reasons and evidence for their opinion.

This study exhibits several limitations that should be taken into account when interpreting our findings and conducting future research. Our sample was limited to women whose CPM procedures were conducted in a single geographic region, and who were mostly white. Future research should continue to examine how factors such as race and socioeconomic status affect CPM decisions. In addition, all of our interviewees elected CPM, and we report on a decision that was made as much as 6 years before participation in the study. Over time, choice-supportive bias³⁵ may have resulted in diminished memory of interactions that were less positive toward CPM, skewing participants' reports in a pro-CPM direction. Addressing this limitation in our work will likely require that researchers study women who are in the process of making their treatment decisions. Comparing women who strongly considered CPM but ultimately chose breast conservation or unilateral mastectomy with those who chose CPM, Hawley et al³⁶ reported that those who chose CPM were significantly more likely to be "very worried about recurrence" (93.8% vs. 80.1%, $P=0.001$). Nevertheless, 4 out of 5 women who did not choose CPM were still "very worried about recurrence," but chose another surgical therapy suggesting there were additional considerations affecting their decisions. To guide surgeon's consultations, future research should also examine why women decide against CPM, who influences them, and especially how women who initially wanted CPM are dissuaded (ethically and compassionately) from pursuing this path.

Identifying the individuals who exert the greatest influence and the type of influence they exert provides an additional opportunity for medical professionals, in general, and surgeons, in particular, to dampen and reverse the increase in CPM. These individuals can be partners in this endeavor by reinforcing the information provided to the patient. From a surgeon's perspective, it would be far preferable to use information, social networks, and social media to reduce CPMs rather than having the same result imposed by payers.

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