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# Increase in contralateral prophylactic mastectomy conversation online unrelated to decision-making



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### ABSTRACT

**Background:** The increased uptake of contralateral prophylactic mastectomy (CPM) among breast cancer patients remains poorly understood. We hypothesized that the increased rate of CPM is represented in conversations on an online breast cancer community and may contribute to patients choosing this operation.

**Methods:** We downloaded 328,763 posts and their dates of creation from an online breast cancer community from August 1, 2000, to May 22, 2016. We then performed a keyword search to identify posts which mentioned breast cancer surgeries: contralateral prophylactic mastectomy ( $n = 7095$ ), mastectomy ( $n = 10,889$ ), and lumpectomy ( $n = 9694$ ). We graphed the percentage of CPM-related, lumpectomy-related, and mastectomy-related conversations over time. We also graphed the frequency of posts which mentioned multiple operations over time. Finally, we performed a qualitative study to identify factors influencing the observed trends.

**Results:** Surgically related posts (e.g., mentioning at least one operation) made up a small percentage ( $n = 27,678$ ; 8.4%) of all posts on this community. The percentage of surgically related posts mentioning CPM was found to increase over time, whereas the percentage of surgically related posts mentioning mastectomy decreased over time. Among posts that mentioned more than one operation, mastectomy and lumpectomy were the procedures most commonly mentioned together, followed by mastectomy and CPM. There was no change over time in the frequency of posts that mentioned more than one operation. Our qualitative review found that most posts mentioning a single operation were unrelated to surgical decision-making; rather the operation was mentioned only in the context of the patient's cancer history. Conversely, the most posts mentioning multiple operations centered around the patients' surgical decision-making process.

**Conclusions:** CPM-related conversation is increasing on this online breast cancer community, whereas mastectomy-related conversation is decreasing. These results appear to be primarily informed by patients reporting the types of operations they have undergone, and thus appear to correspond to the known increased uptake of CPM.

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## Background

The rising rate of contralateral prophylactic mastectomy (CPM) is a well-established phenomenon in the United States. Gemal *et al.*<sup>1</sup> examined the National Inpatient Sample and found that the rate of CPM in the setting of unilateral breast cancer rose from 39 to 207 per 1000 mastectomies between 1998 and 2008. During this same interval, the rates of unilateral mastectomy have decreased.<sup>2</sup> Similarly well-studied is the relatively low risk of breast cancer recurrence in BRCA-negative women with early stage cancer treated with breast conserving surgery and adjuvant systemic therapy.<sup>3–6</sup> In spite of this information, women who would otherwise be good candidates for breast conserving therapy are requesting CPM at increasing rates over the last decade, despite a lack of evidence for improved survival and a greater risk of perioperative complications from the procedure.<sup>7</sup>

The increased uptake of the procedure continues to perplex breast surgeons, many of whom report discomfort with performing CPM at some point during their career.<sup>8</sup> In addition, while most patients who have undergone the procedure report that they would choose it again, many do report unanticipated negative consequences of the procedure.<sup>9</sup>

Prior studies have identified factors associated with increased uptake of CPM including: age <50 y, White ethnicity, family history of breast cancer, BRCA1/2 mutation testing, invasive lobular histology, clinical stage, use of reconstruction, tumor size, multicentric disease, surgeon gender (female), undergoing magnetic resonance imaging and experiences of family/friends with cancer.<sup>10–14</sup> In addition, some researchers have hypothesized that exposure of patients to online information may be leading to an increased rate of the procedure.<sup>6</sup>

Research has demonstrated that approximately 40% of breast cancer patients report some or frequent online communications.<sup>15,16</sup> Schmidt *et al.*<sup>17</sup> found that patients who used the Internet more frequently were more likely to undergo a bilateral mastectomy.

Online health communities (OHCs) are interactive forums on the Internet where patients, caregivers, and others can turn to receive information as well as emotional support.<sup>18</sup> Similar to in-person support groups, they have been shown to benefit breast cancer patients by decreasing depression, cancer-related trauma, and perceived stress.<sup>19</sup> For researchers, OHCs serve as a rich data source, providing insight into patient decision-making, temporal trends, and concerns expressed by caregivers.

We sought to identify if the rate of conversation about CPM on an OHC was increasing and what factors may be contributing to the trends we observed.

## Methods

After the institutional review board approval, we developed a JavaScript Object Notation–based script to automatically download posts ( $n = 328,763$ ) from a well-known, publicly available online breast cancer community from January 2000 to May 2016. JavaScript Object Notation is a programming language that enables the execution of customized, automatic

downloads of Web page content. Each post was linked with time and date of creation, screen name of author, and thread that the post belonged to. We then performed a keyword search of all posts to identify those mentioning operations (Table 1). Keywords were selected based on common terminology used to refer to the operations as well as a key posted on the community to help users identify relevant posts. The first author validated the results by manually reviewing 50 randomly selected posts for each procedure to ensure that the keywords used in the resulting posts matched our intended use of the keyword (e.g., “double” referred to bilateral mastectomy and not two of something else). All 150 randomly selected posts used the keywords in concordance with our intended meaning.

Next, we study the trends of surgery-related posts that mention one or multiple operations. Given certain pattern of operations, their trends over time are evaluated by two metrics: the incidence rate ratio (IRR) and the association between the counts of surgery-related posts (CSRP) and time based on the Cochran–Armitage test.<sup>20,21</sup> Here, we consider two different categories of patterns of operations: (1) one target operation was mentioned (e.g., including the keyword of CPM) in a post and (2) multiple target operations were mentioned (e.g., mentioning both CPM and mastectomy) in a post. A list of possible patterns has been listed in Table 2. We perform the evaluation on a yearly basis using the CSRP based on the above previously mentioned patterns. Table 2 shows a contingency table for CSRP under a certain pattern of operations  $P_j$  within  $K$  consecutive years from  $t_1$  to  $t_K$ . For year  $t_i$ , let us denote by  $n_{i1}^j$  and  $n_{i0}^j$  CSRP with the pattern  $P_j$  or not, respectively. In addition, we define  $N_i^j = n_{i0}^j + n_{i1}^j$  as the total CSRP in year  $i$  for pattern  $P_j$  and  $n_{i1}^j/N_i^j$  as the incidence rate for year  $i$ . Afterward, IRRs can be calculated based on the incidence rates, which measure the trend of percentages of a given pattern  $P_j$  among total posts. Given a period of time from  $t_i$  to  $t_l$ ,  $1 \leq i < l \leq K$ , IRR is calculated by

$$IRR = \exp \left[ \log \frac{\left( \frac{n_{i1}^j}{N_i^j} \right)}{\left( \frac{n_{l1}^j}{N_l^j} \right)} / (l - i) \right] \quad (1)$$

Generally, it shows an increasing trend when  $IRR > 1$ ; otherwise, it indicates a decreasing trend.

Moreover, we also perform Cochran–Armitage test to evaluate the association between CSRP of each pattern and time. Let us denote by  $R_1^j$  and  $R_0^j$  the total CSRP with or without pattern  $P_j$  within  $K$  consecutive years, respectively. The trend test statistic  $\tau$  is estimated by  $\tau = \sum_{i=1}^K (n_{i1}^j R_0^j - n_{i0}^j R_1^j)$ . Then, the variance can be computed by

**Table 1 – Keywords used to identify posts.**

Operation	Example keywords
CPM	Bilateral, contralateral, prophylactic, double, CPM, mastectomy, BPM
Mastectomy	Mastectomy, mast, MX
Lumpectomy	Lump, lumpectomy

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