TITLE: Understanding Breast Implant Illness via Social Media Data Analysis

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ABSTRACT

**Background:** Breast implants have been increasingly popular over the last 20 years. There have been growing concerns with the risks of breast implants. Meanwhile, media phenomenon called “breast implant illness” (BII) has emerged.

**Objective:** To identify and summarize key attributes of BII using social media data.

**Materials and Methods:** We conducted social media data analysis to better understand the symptoms, signs, etc., that are associated with BII using Natural Language Processing (NLP) and topic modeling. We extracted mentions related to signs/symptoms, diseases/disorders and medical procedures using the Clinical Text Analysis and Knowledge Extraction System (cTAKES). Extracted mentions are mapped to standard medical concepts. We summarized mapped concepts to topics using Latent Dirichlet Allocation (LDA).

**Results:** Our analysis identified topics related to toxicity, cancer and mental health issues that are highly associated with breast implant illness. We also identified pains and other disorders commonly associated with breast implant illness.

**Discussion:** Our analysis suggests that breast implant illness can possibly lead to serious health issues such as autoimmune disorders, cancer, pain, fatigue. We also find that toxicity from silicone implants and mental health concerns are some underlying factors in BII. Our study could inspire future work to further study the suggested symptoms and factors of BII.

**Conclusion:** Our analysis over social media data identifies mentions such as rupture, infection, pain and fatigue that are considered common self-reported issues among the public. Our analysis
also shows that cancers, autoimmune disorders and mental health problems are emerging concerns, albeit less studied for breast implants.

**BACKGROUND AND SIGNIFICANCE**

Breast implants have been increasingly popular over the last 20 years.[1] More than 400,000 women have breast augmentation or post mastectomy surgeries every year in the US.[1] There has been a 4% increase in the number of breast augmentation procedures during 2017-2018, and over the same period a 6% increase in the breast implant removal procedures.[1] Concerns about the safety of breast implants have also arisen[2–7] and persisted[8–14], although a causal link between breast implants and systemic diseases has not been definitively shown. Meanwhile, a phenomenon called “breast implant illness” (BII) has emerged.[15] Unlike other possible medical illnesses, however, BII has been reported minimally in the medical literature,[16–18] and has primarily come to attention on social media[19–23]. The lack of medical reports about BII makes it difficult to define the condition and therefore nearly impossible to conduct rigorous epidemiological or clinical studies of it.

Toward identifying and summarizing key attributes of BII and developing patient-centered language to understand and communicate about BII, in this study, we conducted social media data analysis to better understand the symptoms and signs that are associated with BII using Natural Language Processing (NLP) and topic modeling methods. Given the fact that the medical knowledge and literature on BII have not been established, and the related concepts are not well defined or well accepted, using social media data to understand emerging issues could
be a meaningful starting point. Our study provides the first analysis, to the best of our knowledge, using NLP over social media data and derived knowledge of BII from social media and demonstrates the potential of using social media information to better understand conditions that have primarily been reported on social media, rather than the medical literature.

MATERIALS AND METHODS

We collected and used data from the following social media websites. These websites are selected because they are dedicated for BII discussions and information and have focused user groups with interest in BII.

- https://www.breastimplantillness.com: this is a dedicated, public website with articles on BII-related topics, and offers resources related to implant and explant procedures, etc. This website also allows individuals to post their experiences and concerns on breast implants and related health issues. We extracted individuals’ posts from the website (up to 05/10/2019), and the resulted dataset is referred to as BIIweb.

- https://healingbreastimplantillness.com: this website contains information on post-implant disorders, post-explant healing, breast implant safety, etc. The discussion board of this website has multiple posts and comments on symptoms, signs, etc., that are experienced by individuals with a breast implant or those who have undergone an explant. The dataset extracted from the discussion board of this website (up to 05/10/2019) is referred to as HealingBII.
https://www.instagram.com/explore/tags/breastimplantillness: this website contains the collection of publicly available Instagram posts that used “breastimplantillness” as a hashtag in their posts. We extracted the associated texts of each Instagram post with the timestamp between 01/10/2012 and 09/04/2019. The dataset extracted from this site is referred to as IG-BII.

Table 1: Statistical Summary of Social Media Data Analyzed

| Dataset   | Raw data | after cTAKES annotation |
|-----------|----------|-------------------------|
|           | #posts   | #max | #min | #avg | #words | #cwords | #annots | #maps | #M | #C | #M/#C | #C/#M | #S | #D | #P |
| BIIweb    | 187      | 669  | 3    | 129  | 24,191 | 24,034  | 2,186  | 661   | 640 | 475 | 1.39  | 1.03  | 385 | 149 | 106 |
| HealingBII| 1,920    | 1,330| 1    | 85   | 165,090| 1,63,352| 11,080 | 1,740 | 1,685| 1,177| 1.48  | 1.03  | 891 | 503 | 292 |
| IG-BII    | 28,987   | 515  | 1    | 123  | 3,581,081| 3,116,966| 185,339 | 5,694 | 5,530| 2,871| 1.98  | 1.03  | 3049| 1.549| 932 |

In this table, #posts indicates the number of posts/comments in the respective datasets; #max/#min indicates the maximum/minimum length of a post in terms of words; #avg indicates the average length of posts in terms of words; #words indicates the total number of words in respective datasets; #cwords indicates the total number of words recognized by cTAKES; #annots indicates the total number of extracted mentions belonging to the three semantic types (i.e., signs/symptoms, diseases/disorders and medical procedures); #maps indicates the number of unique mention-CUI mappings; #M indicates the number of unique extracted mentions; #C indicates the number of unique mapped concepts; #M/#C indicates the average number of unique extracted mentions mapped to a given CUI; #C/#M indicates the average number of unique CUIs mapped to an extracted mention; #S indicates the number of unique extracted mentions that are mapped to the signs/symptoms category; #D indicates the number of unique extracted mentions that are mapped to the diseases/disorders category; #P indicates the number of unique extracted mentions that are mapped to the medical procedures category.

All comments/posts from the three websites are included in the corresponding datasets. A summary of the datasets is presented in the columns under “raw data” in Table 1. The BIIweb dataset has only 187 posts but larger posts (larger #avg) on average than the other two datasets. HealingBII is the second largest dataset with 1,920 posts, each with 85 words on average. IG-BII is the largest dataset with 28,987 posts and 123 words per post on average. We used the NLTK tokenizer[24] and the NLTK English stopwords list to filter raw texts. Then, we extracted major topics of interest primarily related to symptoms, diseases and medical procedures from our datasets through the following two steps.
1. Concept Mapping: We extracted mentions related to signs/symptoms, diseases/disorders and medical procedures using the Clinical Text Analysis and Knowledge Extraction System (cTAKES).[25] Extracted mentions are further mapped to standard medical concepts that are represented by concept unique identifiers (CUIs) in the Unified Medical Language System (UMLS)[26] ontology.

2. Topic Modeling: We summarized mapped concepts to topics using Latent Dirichlet Allocation (LDA).[27] LDA is a probabilistic generative model for topic modeling. It represents each document as a mixture over latent topics, where each topic is modeled as a distribution over words. Thus, given the corpus of the mapped concepts, LDA generates documents-topics and topics-concepts probability distributions. We further analyzed these distributions to derive topics using most representative mentions, thereby summarized extracted mentions for each data.

Figure 1: Pipeline for Breast Implant Illness Social Media Analysis
Figure 1 presents the pipeline of our methods. We will discuss the methods in detail below.

**Concept mapping**

We first removed all the numeric characters, emojis, non-ASCII characters, hyperlinks, hashtags and Twitter handles using regular expression matching, and converted all the remaining characters into lower case. We then annotated the processed data using the fast-dictionary-lookup annotator in cTAKES. The cTAKES tool is an open-source NLP tool for clinical information extraction from unstructured clinical texts. Its fast-dictionary-lookup annotator identifies mentions in texts and normalizes them into the codes in the UMLS standard medical ontology. It also categorizes each mention into one of five cTAKES categories: sign/symptom, disease/disorder, medication, procedure and anatomy. We configured the annotator to use exact string match and to use all-term-persistence property. Thus, the annotator retains all terms irrespective of the semantic properties of each term. For example, for the text “headache”, the annotator annotates the generic term “ache” as well as the precise term “headache”. We chose to use the all-term-persistence property to retain maximum information with respect to precise and generic medical concepts. Finally, the annotator stores the generated annotations in XMI files.

In order to obtain the annotations in a human-readable format from the XMI files, we performed the following steps. We used a custom interpreter to process XMI files produced by cTAKES and to generate mappings between mentions and CUIs. We first looked for `UmlsConcept` XML identifiers in the XMI files, where each `UmlsConcept` XML identifier is generally grouped under the `FSArray`, and each `FSArray` is associated with a single ontology concept and the category of the concept. It must be noted that a mention can be mapped to
multiple CUIs. For example, the mention “allergic reaction” is categorized as sign/symptom but mapped to two different CUIs “C1527304” and “C0020517”. Then, we extracted those ontology concepts that describe any of these categories: diseases/disorders, signs/symptoms and medical procedures in order to understand BII. Finally, we used the begin and end markers associated with each ontologyConceptArr identifier to obtain the position of the annotated mention in the input text file.

**Topic modeling**

In order to conduct topic modeling, we processed the posts as follows: we substituted each mention in the posts with its mapped CUIs and discarded all the other words in the posts. If a mention was mapped to multiple CUIs, we replaced that mention with the multiple CUIs. Therefore, the posts were represented as a bag-of-CUIs instead of a collection of mentions, and our vocabulary consisted of CUIs. Also, we maintained per post a frequency count of each CUI occurring in that post. Upon topic modeling, we interpreted the topic-CUI distribution to derive the topics using the most representative mentions.

We used Latent Dirichlet Allocation (LDA)[27] to summarize the extracted mentions into representative topics. LDA assumes that a document of \( N \) words \( \mathbf{w} = \{w_1, w_2, \ldots, w_N\} \) (in our case, a post of CUIs) is generated as follows: 1) a per-document distribution over topics \( \mathbf{\theta} \in \mathbb{R}^K \) is first sampled from a Dirichlet distribution \( \text{Dirichlet}(\mathbf{\alpha}) \), where \( \mathbf{\alpha} \in \mathbb{R}^K \) is the Dirichlet prior \( \alpha_k \geq 0 \ (k = 1, \ldots, K) \) and \( K \) is the given number of topics; 2) for each word \( w_i \) in the document, a topic \( z_i \) is sampled from a multinomial distribution \( \text{Mult}(\mathbf{\theta}) \); 3) a word distribution \( \mathbf{\phi}_i \in \mathbb{R}^L \) over topic \( z_i \) is sampled from a Dirichlet distribution \( \text{Dirichlet}(\mathbf{\beta}) \), where \( \mathbf{\beta} \in \mathbb{R}^L \) is the Dirichlet
prior, \( \beta_l \geq 0 \) \((l = 1, \ldots, L)\) and \( L \) is the number of words in the vocabulary; 4) given \( \phi_l \), word \( w_l \) is sampled from a multinomial distribution \( \text{Multi}(\phi_l) \). LDA assumes all the words \( w_l \) in a document are independent given their \( \phi_l \), and all the documents in the corpus are independent. Estimation on \( \theta \) and \( \phi \) via maximum likelihood methods will enable document topics and the most probable words over the topics. We used lda-c software\cite{28} that implements LDA to generate topics in our experiments.

**RESULTS**

**cTAKES annotations**

Columns under “after cTAKES annotation” in Table 1 present the summary statistics on the annotated mentions and mapped concepts out of cTAKES. For BIIweb, cTAKES extracted 2,186 mentions and mapped those to 475 unique medical concepts (i.e., CUIs). For HealingBII, cTAKES extracted 11,080 mentions and mapped those to 1,177 unique CUIs. For the largest dataset IG-BII, cTAKES extracted 5,530 unique mentions and 2,871 unique CUIs. We observed that cTAKES often associates a single mention with multiple CUIs belonging to the same category. We think it is due to the presence of multiple mappings for a given mention in the UMLS meta-thesaurus. Please note that a same mention can also be mapped to different categories. For example, the mention “flashes” is mapped to two different categories: diseases and medical procedures. Table 1 also presents the statistics of each category of extracted
mentions. BIIweb and IG-BII have more sign/symptoms related mentions, and HealingBII has more diseases/disorders related mentions.

**LDA topics**

In order to find the best topic models, we used grid search to identify the best parameter values for the Dirichlet prior $\alpha \in \{0.01, 0.05, 0.1, 0.5, 1, 1.5, 2, 5, 10, 15, 20, 25\}$ and the number of topics $K \in \{3, 4, 5, 10, 15, 20\}$. We used the popular perplexity criteria to evaluate a topic model, as lower perplexity typically indicates better modeling. However, we noticed that LDA of lowest perplexity does not always enable intuitive or meaningful topics. Therefore, we evaluated each LDA topic modeling result and interpreted the document-topic and topic-CUI probability distributions out of low-perplexity LDA modeling to derive meaningful topics. We further evaluated the quality of a topic model based on how well the derived topics summarize the most representative mentions using domain knowledge. Finally, we identified distinct meaningful topics using (i) $K = 4$ and $\alpha = 10$ for BIIweb, (ii) $K = 5$ and $\alpha = 10$ for HealingBII and (iii) $K = 5$ and $\alpha = 1.5$ for IG-BII. Tables 2, 3 and 4 present the top-10 representative mentions, their occurrence probabilities and our interpretations for each topic in respective datasets. Note that we used CUIs in LDA to derive topic and word distributions, and we present the most frequent mentions that are mapped to respective CUIs in these tables. These mentions (CUIs) are sorted based on their probabilities belonging to the respective topics (note that the probabilities in these tables are the occurrence probabilities of the mentions, not their probabilities in topics). Therefore, each topic is represented by its most representative mentions and thus summarizes such mentions. For example, we interpret a topic as pain and other signs if there are significant
number of mentions related to pain such as neck pain, chest pain, headache, etc. Below, we discussed the derived topics out of LDA for BIIweb and HealingBII datasets with examples from the original posts. Note that two topics can still share a same representative mention with different probabilities in LDA.

### Table 2: Derived Topics in BIIweb

| topic | top-10 mentions | interpretation |
|-------|-----------------|----------------|
| 1     | testing (2.34); illness (4.46); problem (2.82); swollen (0.78); drains (0.61); feel common (2.51); fatigue (1.82); exhausted (0.39); sensitivity (0.95) | common signs/symptoms |

Example: “I had silicone implants done 5 years ago, three years ago after going to the doctor with extreme *fatigue* (I was sleeping 14-16 hours a day and was still *exhausted*)”

| 2     | breast implant (6.8); removal (1.3); cancer (0.95); autoimmune (0.95); infection (0.87); scleroderma (0.39); pain (3.68); diagnosis (0.3); alcl (0.3); breast cancer (0.3); | diseases/disorders |

Example: “I had stage 4 breast *cancer* and had chemo and radiation. I tried to have my breast implants removed due to *pain*. Then I had an acute *infection* occur a month and a half after they put the new implants in and they were forced to perform an emergency *removal* of the newer implants. I have had all the symptoms of breast implant *illness* – even after their removal.”

| 3     | breast implant (6.8); illness (4.46); toxicity (1.17); foreign body (0.87); heal (0.78); support (0.65); rupture (0.52); cancer (0.95); awareness (0.35); inflammation (0.56) | toxicity |

Example: “...I never had a problem until 2006 at which time I thought something had happened however, my surgeon said I must have just pulled a muscle and that the *implants* seemed fine. Now that surgeon is old and the shop is closed up. I have been suffering for the past 13 years with arthritis, *fatigue*, brain fog, *inflammation*, hormone imbalances, and adrenal fatigue...”

| 4     | pain (3.68); feel (2.51); fatigue (1.82); back pain (0.87); illness (4.46); joint pain (0.56); worse (0.65); anxiety (0.52); ear ringing (0.39); headache (0.39) | pain and stress-related disorders |

Example: “It wasn’t until 2017 where I started to experience *anxiety* and panic attacks (which I didn’t know I was having at the time). With that, along came crazy *headaches*, feeling dizzy, sick, lightheaded and my right eye would always be swollen and never knew why.”

In this table, the numbers in parentheses are probabilities (in %) of occurrence of the corresponding CUIs in the posts, not the probabilities of the CUIs belonging to the respective topics. The mentions (CUIs) are sorted based on their probabilities belonging to the respective topics. Examples are provided as
representative posts from website users that have high probabilities of belonging to the respective topic compared to any other topics, with the words underlined that have high probabilities of belonging to the respective topic.

Table 2 presents the topics in dataset BIIweb. Recall that BIIweb is the smallest dataset (Table 1). Even though, we were able to identify distinct topics. Most of the representative mentions in BIIweb include, for example, fatigue, infection, toxicity, anxiety. Table 3 presents the topics in dataset HealingBII. HealingBII shares some common topics/representative mentions as those in BIIweb. For example, pains, cancers and toxicity are common across these two datasets. However, a focused topic unique in HealingBII is on surgeries and procedures, where people (mostly patients) discuss the procedures among themselves and share related experiences. Another unique topic in HealingBII is on mental health.

Table 3: Derived Topics in HealingBII

| topic                                   | top-10 mentions                                                                 | interpretation               |
|-----------------------------------------|--------------------------------------------------------------------------------|------------------------------|
| 1                                       | rupture (1.34); supported (0.87); read (1.17); suffering (0.87); happy (0.6); mastectomy (0.46); work (0.96); scare (0.77); reconstruction (0.41); mri (0.72) | surgeries and procedures     |
| Example:                               | “Double mastectomy in 2015. Reconstruction process with expanders then permanent 1000 ml saline implants in early 2016. After that was 9 procedures, a hysterectomy and now MANY health problems.” |
| 2                                       | pain (3.91); joint pain (0.79); fatigued (0.96); ailment (4.7); removal (0.84); hair loss (0.52); headache (0.47); muscle ache (0.34); rash (0.39); infection (0.84) | pain and other signs         |
| Example:                               | “In addition to the neuromuscular spasms and pain, I’ve suffered with incapacitating chronic fatigue, BRAIN FOG and confusion (yes, even while driving), loss of vision and hearing, vertigo, mysterious skin rashes, hair loss, migraines, ...” |
| 3                                       | problem (2.64); cancer (0.9); autoimmune (0.57); breast cancer (0.38); scars (0.35); treatment (0.43); diagnose (0.29); autoimmune disorder (0.27); lupus (0.29); arthritis (0.26) | cancer and other disorders   |
| Example:                               | “I had capsules form on both breasts from about 2010. I got sick with BII symptoms from 2005 with lots of infections required intravenous and oral antibiotics. My environmental and drug allergies got worse, onset of arthritis, skin rashes, autoimmune” |
In addition to physical symptoms, individuals reported significant emotional and mental difficulties such as depression and expressed their serious symptoms in social media. Table 4 presents the topics in dataset IG-BII. IG-BII is the largest dataset (Table 1) and has significantly more posts than the other two. We observed that cancers, mental health and toxicity emerged as significant topics in this large dataset, quite consistently with those in HealingBII. In IG-BII, people also discussed their recovery process from issues/events associated with breast implant illness. We identified from these three datasets frequent mentions of rupture, pains and fatigue. We also identified cancers, lupus and autoimmune disorders that are less studied for breast implants.
| topic | top-10 mentions                                                                 | interpretation |
|-------|---------------------------------------------------------------------------------|----------------|
|       | heal (1.46); working (0.9); weighted (1.05); able (0.99); rest (0.37); stress (0.29); exercise (0.28); therapeutic (0.35); sleep (0.36); run (0.23) | physical health |
| 1     | Example: “It’s been 14 months since my explant. The journey to healing hasn’t been an easy one due to setbacks and relapses but better than daily anaphylaxis from getting cold, food, smells, crying, exercise and stress, then add angina attacks from anaphylaxis.” |                |
|       | malignancy (1.1); removal (0.96); scar (0.75); capsulectomy (0.68); rupture (0.43); ciactrice (0.43); acl (0.41); augmentation (0.37); lymphoma (0.35); removal of implants (0.29) | cancer and medical procedures |
| 2     | Example: “The ugly side of breast implants. It’s not a matter of IF you will get sick…. it’s WHEN. implants leak toxic heavy metals without rupture It’s called a gel bleed. Women with implants are 3 times more likely to develop brain, lung and lymphatic cancer than women with implants.” |                |
|       | loving (2.43); happiness (2.11); emotion (1.64); think (1.05); feel (0.87); scare (0.55); confidence (0.35); tired (0.38); emotional (0.27); sensation (0.33) | mental health |
| 3     | Example: “I was scared of looking incomplete. After much deep, inner work on myself, I realized that my worth wasn’t dependent on what I looked like or how big my chest was. I realized that true happiness would come from 100% acceptance of what and who I was,” |                |
|       | breast implant (7.21); ailment (5.67); toxicity (1.67); aware (0.96); felt worse (0.36); test (0.64); foreign body (0.45); alone (0.33); suffering (0.21); complication (0.2) | toxicity |
| 4     | Example: “There are thousands of women finally coming forward about breast implant illnesses. It doesn’t matter if it’s silicone or saline. They all have a silicone shell. We get toxic from the chemical makeup of the silicone, the toxic chemicals that are released when the shell degrades, sick from rupture and sometimes mold.” |                |
|       | pain (2.52); inflammatory reaction (0.89); fatigue (0.83); anxiousness (0.72); allergy (0.43); depression (0.37); joint pain (0.33); autoimmune disorder (0.32); swell (0.43); infection (0.31) | common disorders |
| 5     | Example: “For three years doctors have been unable to diagnose or explain my upper body weakness, hand pain and general inflammation. I have suffered with periods of high inflammation, debilitating fatigue, migraines, unable to lose weight, insomnia, low libido, body and joint pain, hair loss, dry skin, dry eyes, brain fog, etc.” |                |

In this table, the numbers in parentheses are probabilities (in %) of occurrence of the corresponding CUIs in the posts, not the probabilities of the CUIs belonging to the respective topics. The mentions (CUIs) are sorted based on their probabilities belonging to the respective topics. Examples are provided as representative posts from website users that have high probabilities of belonging to the respective topic.
compared to any other topics, with the words underlined that have high probabilities of belonging to the respective topic.

Below, we present the percentage of posts per topic, where a post $d$ is considered as belonging to a topic $z$ if among all topics that $d$ has, $z$ has the highest probability.

- **BIIweb**: Around 33.15%, 14.97%, 26.74% and 25.14% of the total posts are concerned with (i) common signs/symptoms, (ii) diseases/disorders, (iii) toxicity and (iv) pain and stress-related disorders respectively.

- **HealingBII**: Around 37.13%, 11.51%, 11.51%, 26.31% and 13.54% of the total posts are concerned with (i) surgeries and procedures, (ii) pain and other signs, (iii) cancer and other disorders, (iv) toxicity and (v) mental health respectively.

- **IG-BII**: Around 38.98%, 13.42%, 16.83%, 18.68% and 12.09% of the total posts are concerned with (i) physical health, (ii) cancer and medical procedures, (iii) mental health, (iv) toxicity and (v) common disorders respectively.

Although the distributions are not completely consistent across datasets, toxicity remains a notable topic among all the datasets. This indicates the common issues significantly associated with breast implant illness. Also, pains, cancers, mental health and other disorders are substantially associated with breast implants.

**DISCUSSION**

In order to understand signs, symptoms and side-effects associated with breast implant illness, a condition reported primarily in social media rather than medical reports, we collected
social media posts and analyzed them using NLP and topic modeling. We extracted mentions related to signs/symptoms, diseases/disorders and medical procedures using cTAKES, mapped them to standard medical concepts, and summarized mapped concepts to topics using LDA. We found that mentions such as rupture, infection, inflammation, pains and fatigue were common self-reported issues. We also found that mental health related concerns such as stress, anxiety and depression and cancers and autoimmune disorders were common concerns.

In our proposed method, we relied on cTAKES and the rich UMLS dictionary to extract all relevant mentions including their lexical variants (synonyms, abbreviations, paraphrases). It is worth noting that we did not evaluate the performance of our mention extraction module, which is typically done using precision and recall metrics when there are ground-truth labels associated with each mention. However, in order to have such labels, it requires careful manual annotations based on domain knowledge on breast implant illness. Unfortunately, such domain knowledge on complications, symptoms and other issues associated with/caused by breast implant illness is not fully available. Actually, our goal in this study is to provide useful information from social media data that could help complement what we currently know. Therefore, in this preliminary study, we use all the annotated mentions, assuming that cTAKES enables high-quality annotations. We acknowledge that cTAKES might not be able to extract all relevant mentions from our social media datasets. This is because that cTAKES was originally designed for extraction of medical entities from clinical notes, which have very different wording and writing styles compared to social media data. As social media data comprise informal phrases, short ambiguous texts, emoticons and wide range of lexical variants corresponding to a single concept,
cTAKES may not work flawlessly on social media data, although we observed reasonable output out of cTAKES. Regardless, the extracted mentions and the mapping of mentions to UMLS CUIs as generated by cTAKES are used for topic modeling without any manual verification or evaluation. In the future research, we will develop a detailed guideline to further evaluate extracted mentions before using them in topic modeling.

Our study also has some limitations. First, LDA is an unsupervised learning technique, in which the number of topics ($K$) is assumed to be known a-priori. However, it is difficult to accurately estimate $K$ for a given dataset. In our study, we used grid search to try different $K$ values. Even though, without full domain knowledge, it still remains non-trivial to evaluate the LDA results for each $K$ value. The results we presented correspond to low perplexity scores (but not necessarily the lowest) and with interpretable/intuitive topic meanings. In the future research, we will develop more rigorous ways to select the number of topics and to evaluate topic modeling results. In our current study, we did not do a sentiment analysis on the posts. We plan to do it before topic modeling so as to generate cleaner dataset for topic modeling.

It is always worth noting that social media data could be of poor quality (e.g., misspelling, misconception, biased opinions), particularly compared to medical literature data. Anyone can post to social media, and so the derived content may be from individuals who may have other implant specific issues such as capsular contracture or implant infection. Thus, understanding side effects, symptoms, signs, etc., associated with a drug, disease or medical procedure from social media data always runs into risks of confounders or errors. However, given that the medical knowledge and literature on breast implant illness have not been well
established, and the related concepts are not well defined or well accepted, using social media data to understand emerging issues could be a meaningful starting point. Still, any findings from social media data require rigorous evaluation and validation based on medical and biological knowledge, experiments and clinical practice, etc. In addition, we only analyzed three, though the most relevant and prolific, websites dedicated to BII discussions. Additional, more comprehensive analysis on social media data of a much larger scale would be beneficial to better understand BII from a larger, diverse population.

This study has important implications for future methodological work and clinical research. Future methodological research on NLP could include causality inference between breast implant illness and symptom/sign mentions from social media to understand their relations, etc. Our findings could be used for clinical research studies that are seeking to develop measures of BII and to identify its causes. Our methodologies and informatics strategies applied in this study would also provide working examples for analyzing other emerging but not well-defined illnesses from social media data.

**CONCLUSION**

Our analysis over social media data identifies mentions such as rupture, infection, inflammation, pains and fatigue that are common self-reported issues among public. In addition, our analysis shows that a significant number of the user comments and posts are also concerned with mental and physical health, and toxicity issues after breast implants. The findings from our study could be used to develop a patient-centered language to better approach patients with
concerns. Our study provides the first analysis and derived knowledge of BII from social media using NLP techniques, and demonstrates the potential of using social media information to better understand emerging illnesses.

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COMPETING INTERESTS

The authors claim no competing interests.
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