

Learning from social media: utilizing advanced data extraction techniques to understand barriers to breast cancer treatment

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Abstract Past examinations of breast cancer treatment barriers have typically included registry, claims-based, and smaller survey studies. We examined treatment barriers using a novel, comprehensive, social media analysis of online, candid discussions about breast cancer. Using an innovative toolset to search postings on social networks, message boards, patient communities, and topical sites, we performed a large-scale qualitative analysis. We examined the sentiments and barriers expressed about breast cancer treatments by Internet users during 1 year (2/1/14–1/31/15). We categorized posts based on thematic patterns and examined trends in discussions by race/ethnicity (white/black/Hispanic) when this information was available. We identified 1,024,041 unique posts related to breast cancer treatment. Overall, 57 % of posts expressed negative sentiments. Using machine learning software, we assigned treatment barriers for 387,238 posts (38 %). Barriers included emotional (23 % of posts), preferences and spiritual/religious beliefs (21 %), physical (18 %), resource (15 %),

healthcare perceptions (9 %), treatment processes/duration (7 %), and relationships (7 %). Black and Hispanic (vs. white) users more frequently reported barriers related to healthcare perceptions, beliefs, and pre-diagnosis/diagnosis organizational challenges and fewer emotional barriers. Using a novel analysis of diverse social media users, we observed numerous breast cancer treatment barriers that differed by race/ethnicity. Social media is a powerful tool, allowing use of real-world data for qualitative research, capitalizing on the rich discussions occurring spontaneously online. Future research should focus on how to further employ and learn from this type of social intelligence research across all medical disciplines.

Keywords Breast cancer · Underserved populations · Race and ethnicity · Adherence · Qualitative research

Introduction

Racial disparities in outcomes for women with breast cancer are persistent and well documented [1, 2]. Evidence suggests that differences in treatment receipt and adherence for black and white patients significantly contribute to disparities in survival [3–8]. Numerous studies have cited complex reasons for the lower observed rates of treatment and adherence for black women, including socioeconomic status (SES), insurance, provider factors, system failures, as well as beliefs and mistrust in providers [3–7, 9–12]. To date, most studies examining barriers to care for diverse populations have been conducted within registry- or claims-based cohorts. Additional smaller studies using surveys, focus groups, and medical records are often limited to a single geographic area or institution and may not necessarily generalize across diverse populations. Furthermore, most surveys have structured formats and are subject to recall bias.

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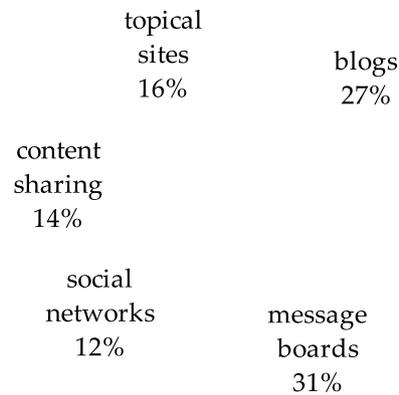


Fig. 1 Types and breakdown of Internet sites included in the analysis ($n = 2021$ sites)

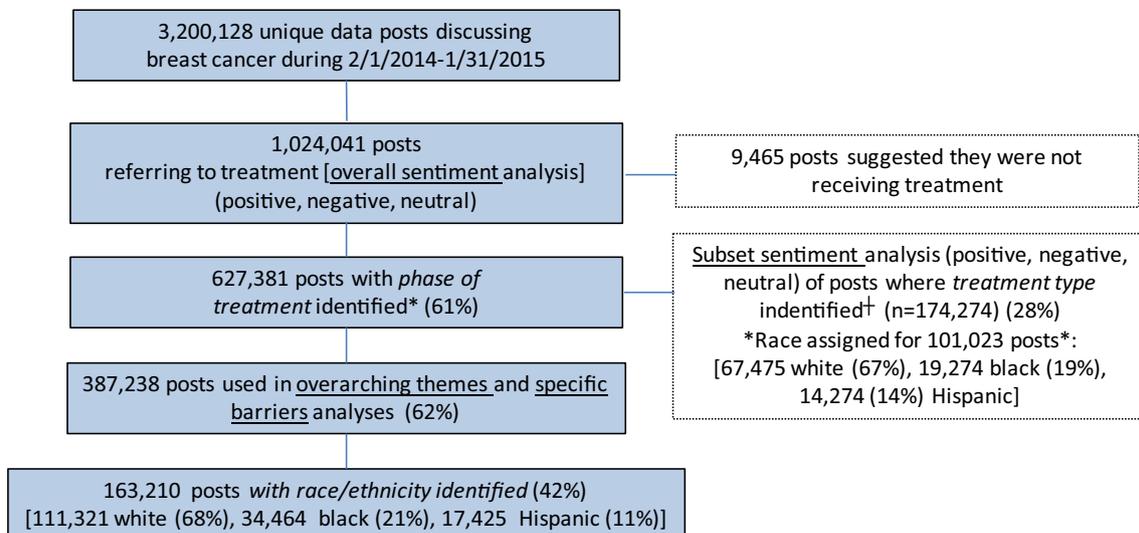


Fig. 2 Schema of included posts for each analytic component*. *Treatment ‘phase’ = pre-diagnosis, diagnosis, assessment, decision to treat, and treatment. †Treatment ‘type’ = overall treatment, surgery, radiation, chemotherapy, hormonal therapy, ‘drugs’ in general

examination of posts for these subgroups of users when possible. Of 387,238 posts with specific themes or barriers assigned, 163,210 had an identified race/ethnicity of the user (white, black, or Hispanic) based on information in the individual’s profile, self-report in posts, or if it was apparent because a post came from a site targeted to Hispanic or black populations. When a user’s race/ethnicity could not be identified, the post was included in ‘overall’ results only.

Content analyses

We first summarized the general attitudes/sentiments (negative/positive/neutral) for all 1,024,041 posts referring to treatment *overall* and the 174,274 posts assigned to a particular treatment (surgery, radiation, chemotherapy, hormonal therapy, ‘drugs’) (subset sentiment analysis) (Fig. 2). Second, we categorized overarching themes discussed by *treatment phase* (pre-diagnosis to treatment) when evident

($n = 387,238$) to examine how barriers might differ over the treatment trajectory. We identified four themes: (a) organizational (previous experiences with healthcare, systems issues), (b) sociocultural (beliefs, family, spiritual, cultural), (c) psychological (emotional), and (d) situational (relating to job, insurance, income, access, other responsibilities). To explore barriers further, we then assigned more specific treatment barriers for the same 387,238 posts *across all treatment phases combined*, including physical, resource, and healthcare perceptions, using the keywords/themes in Supplemental Table. The overarching theme and specific barrier analyses were not mutually exclusive and were overlapping. Finally, we separately examined the subset of 9465 posts (of 1,024,041) that suggested users refused treatment, in case barriers for this group were distinct from those among women undergoing treatment. For all analyses, we examined findings overall and by race/ethnicity when possible (Fig. 2).

Analyses are descriptive in nature and exploratory and no formal statistical tests could be performed. Because we had no identifiable participant information, the study was considered exempt by the Office for Human Research Studies at Dana-Farber Cancer Institute.

Results

Overall and subset sentiment analyses

Among the 1,024,041 posts referring to breast cancer treatment in general, 54 % asked questions ('*Anyone else have path results that were unexpected?*'), 33 % shared content ('*Like you, I am on pins and needles...I am prepared for a cancer diagnosis.*'), and 13 % answered questions ('*Everyone is different, but my port was painful for just a day or two...*'). Overall, 57 % of posts skewed negatively, 31 % were neutral, and 12 % were positive. In a subset sentiment analysis of the 627,381 posts with phase of treatment (pre-diagnosis, diagnosis, etc.) identified, 172,274 posts described a specific treatment (surgery, radiation, etc.). Posts discussed chemotherapy (35 %), surgery (33 %), radiation (15 %), 'drugs' (10 %), and hormonal therapy (7 %) (Fig. 3). Approximately 50 % of all treatment-specific posts skewed negatively; these were most common among posts about surgery or 'drugs'. When race/ethnicity was identified ($n = 101,023$ posts), black users more frequently posted negative comments (66 % of posts) than Hispanic and white users (55 % of posts for each) (Fig. 3).

Overarching themes by treatment phase

The four overarching themes expressed (organizational, sociocultural, psychological, situational as defined above)

by treatment phase (pre-diagnosis to treatment) for the 387,238 posts are shown in Fig. 4. Organizational barriers generally increased from pre-diagnosis (6 % of posts) to diagnosis (13 %) and remained high during assessment (28 %), decisions to treat (21 %), and treatment (29 %). Sociocultural barriers decreased over the treatment trajectory (24 % of posts in the pre-diagnosis phase to 18–20 % of posts about treatments) as did psychological barriers (43 % to 19–25 %). Situational barriers remained relatively constant over the treatment trajectory and were reported in a quarter of posts. Among patients with race/ethnicity identified, psychological, situational, and organizational barriers were most frequent for white users, sociocultural and situational barriers were most frequent for Hispanic users, and situational and organizational barriers were most frequent for black users. Notably, Hispanic and black users experienced more organizational barriers than white users around the time of diagnosis.

Specific barriers to treatment across all treatment phases

A more detailed examination of specific barriers (in contrast to the overarching themes above) among the 387,238 unique posts is shown in Fig. 5. Barriers expressed included emotional (including anxiety, fears, denial, depression; 23 % of posts), personal beliefs (including misinformation, healthcare preferences, spiritual/religious/cultural; 21 % of posts), physical concerns (including limitations, body changes, side effects; 18 % of posts), resource barriers (including costs, logistics, insurance; 15 % of posts), healthcare perceptions (including trust, communication, negative experiences, accessibility of services; 9 % of posts), issues with treatment processes/duration (including complexity, regimen; 7 % of posts), and relationships (including children, friends, intimacy; 7 % of posts).

Numerical differences were noted by race/ethnicity for the 163,210 posts from users with identifiable race/ethnicity, with posts by black and Hispanic users reporting more barriers related to beliefs (24–25 % vs. 21 % of posts by whites) and fewer posts related to emotional (14–17 % vs. 31 %) and relationship (6–9 % vs. 14 %) barriers. Hispanic and black users also reported more barriers related to healthcare perceptions (13 % posts vs. 5 % by white users). Resource barriers were reported with similar frequency for all groups (22–24 % of posts from white/black/Hispanic users), and overall, 49, 46, and 43 % of all posts from black, Hispanic, and white users were related to either resources or beliefs. Table 1 shows representative quotes from each specific barrier.

For *emotional* barriers, most conversations reported fears, anxiety, denial, and depression. Fear was the most common emotional sentiment expressed (35 % of posts)

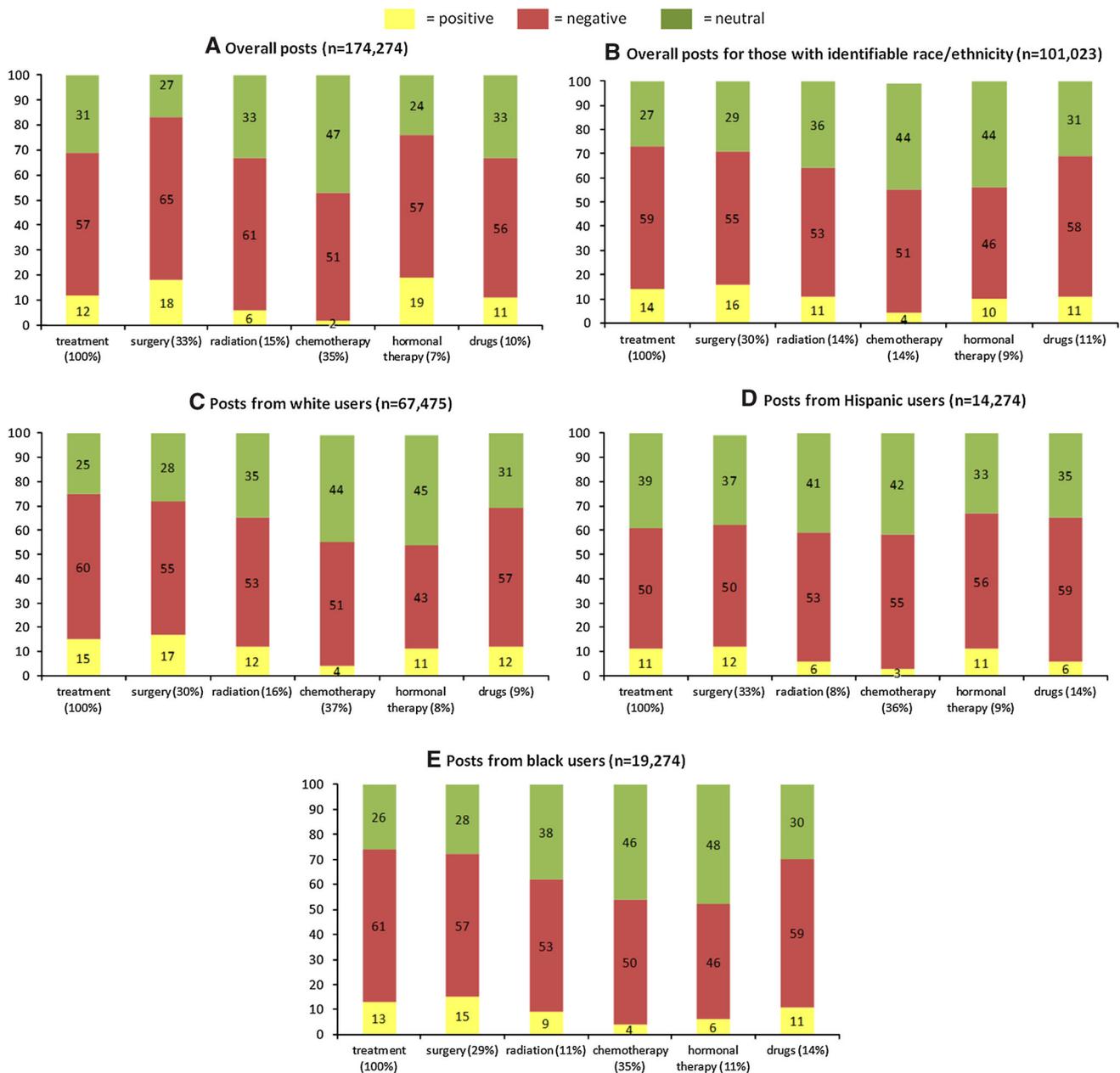


Fig. 3 Percent of general sentiments (positive/negative/neutral) by treatment type [overall (3A, $n = 174,274$ posts) and by race/ethnicity among the users for whom treatment type could be identified* (3B–3E [$n = 101,023$ posts]). *The percent under each treatment bar

and this was the most common emotion expressed by Hispanic users (37 vs. 27 % of black user posts and 33 % of posts by whites). Denial was the most prominent emotion described by black users (32 % of posts), compared with 26 % Hispanic users' posts and 10 % of white users' posts. Posts related to anxiety were most common from white users (31 % posts vs. 20 and 25 % of posts by Hispanic and black patients, respectively).

With regard to *beliefs*, the most common sentiments were spiritual/religious (41 %), although other prominent

represents the percent of posts about treatment that were related to each component of therapy. The *yellow, red, and green bars* represent the proportion of sentiments that were positive, negative, and neutral, respectively

themes included misinformation (30 %) and preferences/perceptions (29 %). Hispanic and white users were more likely than blacks to report spiritual or religious sentiments about treatment (41 and 38 % vs. 31 % of posts from black users) and black users were more likely to express issues with perceptions/preferences (43 % of posts by black users vs. 36 and 33 % posts from Hispanic and white users, respectively).

The most common *physical* concerns expressed were side effects (40 %), followed by physical limitations

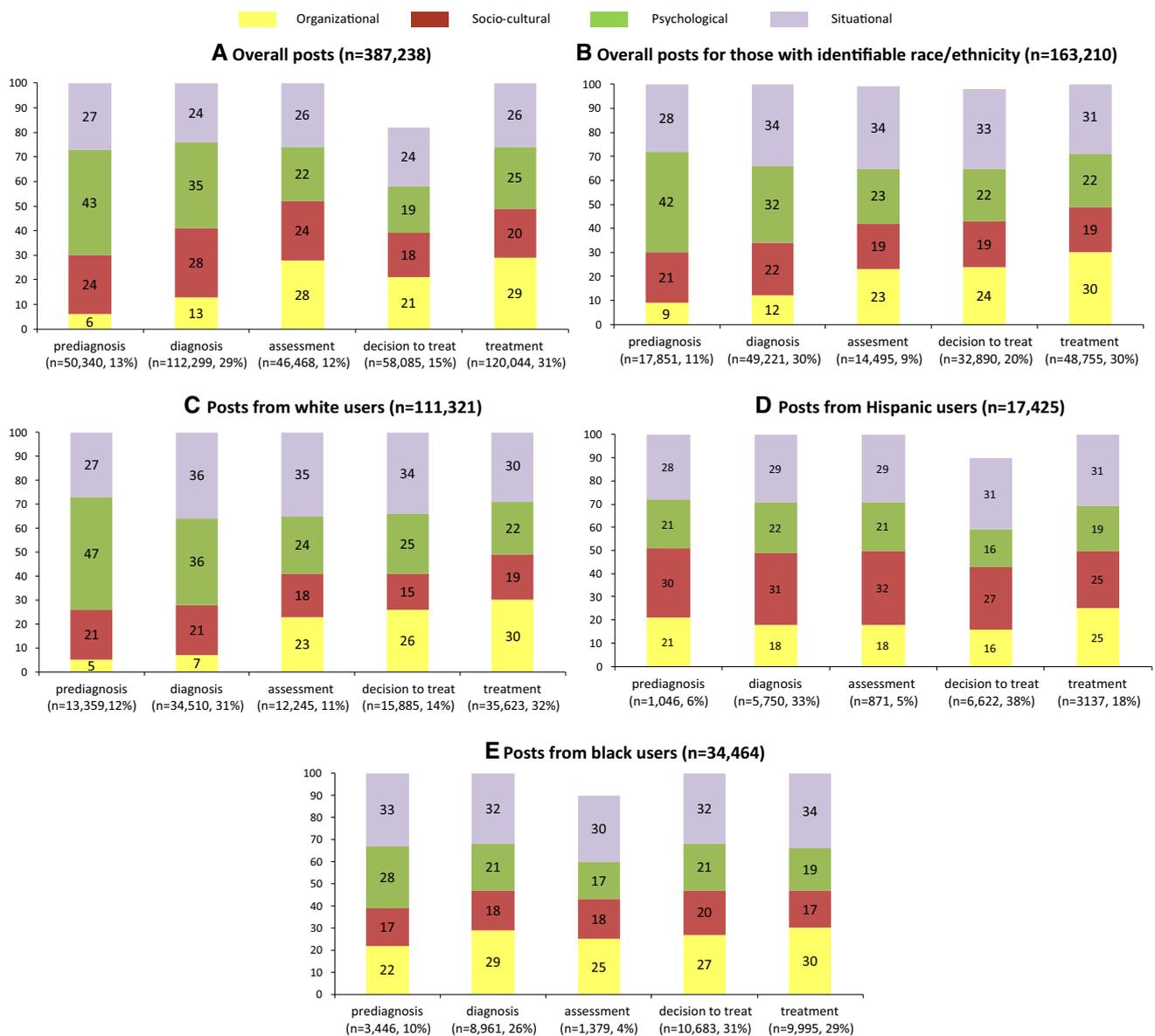


Fig. 4 Profile of barriers[§] by treatment phase and race/ethnicity for 387,238 posts (a) and for those whose race/ethnicity could be identified ($n = 163,210$, 4B–4E)*. [§]Organizational = related to experiences with healthcare and systems issues, sociocultural = related to family/spiritual/cultural influences, psychological = emotional concerns, situational = related to income/insurance/

(31 %) and body changes (29 %). Side effect comments were less frequent in posts by black (30 %) and Hispanic users (29 %) compared with 43 % posts by white users. Body image was most apparent in posts by Hispanics (36 %), while physical limitations were most frequently reported in posts by black users (38 vs. 33 % and 35 % from white and Hispanic users).

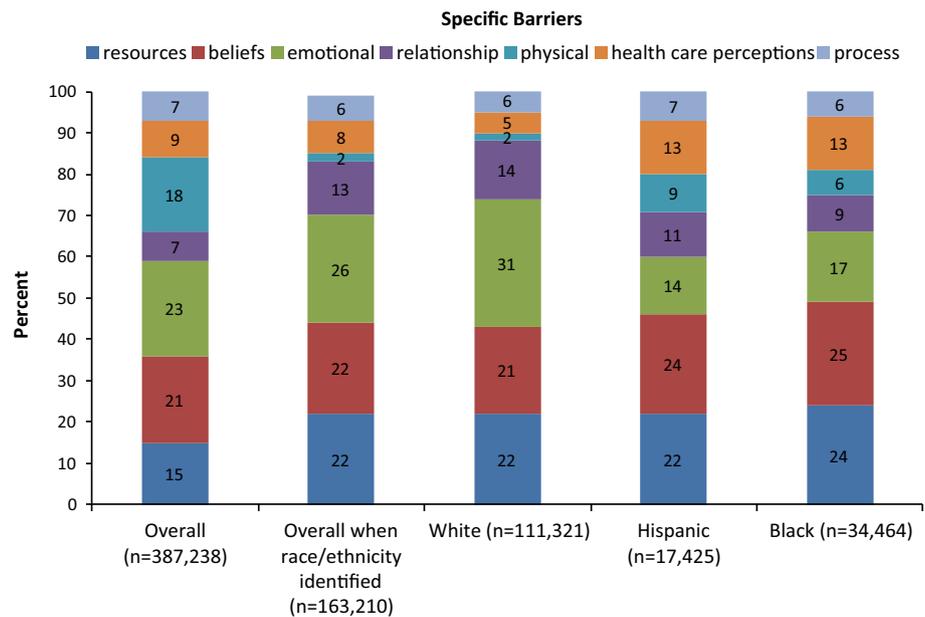
Resource concerns included posts about insurance (49 %), costs (33 %), and logistics of treatment (18 %). Black and Hispanic user posts more often included cost barriers (45 % of posts from black and 41 % of posts from

accessibility/employment/responsibilities. *The percent under *each bar* represents the percent of posts about that phase. The *yellow bars* represent organizational, the *red bars* represent sociocultural, the *green bars* represent psychological, and the *purple bars* represent situational

Hispanic users vs. 32 % of posts from whites) and logistics barriers (28 and 25 % vs. 16 % of posts from white users).

Dominant concerns raised within posts about *health-care perception* barriers included poor communication (36 %), trust (22 %), accessibility of services (21 %), and negative experiences (21 %). Concerns about trust were more commonly mentioned by black and Hispanic users (31 and 29 % of posts) vs. white users (26 %); accessibility concerns were raised in 29 % of posts by black and Hispanic users compared with 20 % of posts by white users.

Fig. 5 Specific barriers to treatment (%) ($n = 387,238$) and by race/ethnicity when identified ($n = 163,210$)



Among posts related to *relationship* barriers, the most dominant issues included problems with intimacy (35 %), friends (34 %), and children (31 %), with intimacy issues being most commonly reported in posts by black and Hispanic users (39 and 37 % vs. 29 % of posts by whites), while issues with friends and children were more frequently reported in posts by whites (71 % of posts) than minority users (61–65 % of posts).

Duration and process barriers were categorized as issues with the regimens prescribed (41 %), duration of treatment (23 %), aftereffects of treatment (19 %), and complexity of care (17 %). Complexity of care was more prominently reported in posts by black and Hispanic users (29 and 23 % vs. 19 % of posts by white users).

Users refusing treatment

In 9465 posts, users suggested that they refused recommended treatments for their breast cancer. Dominant themes in these conversations included fear of side effects (*...enduring treatment would be worse than death for me.*), denial (*I decided this is MY life and I WILL have it MY WAY!*), holistic beliefs (*I'm a 54 year old who refuses treatment because the protocols of treatment are barbaric to me. I've studied a nutritionally holistic approach and I firmly believe I must refuse the traditional approach.*), preferences (*I will not put myself or my family through the seemingly endlessness of treatment, the visits to hospitals, and the entire set of difficult logistics just to prolong my life.*), fatalism (*I think chemo is the biggest scam in the world and millions of people are being told to take it when in fact it will do nothing.*), and faith (*All I need is prayers*

and strength from my family, friends, and my church family).

Discussion

Using a novel, comprehensive analysis of over 1 million posts about breast cancer treatments from a diverse population of social media users, we observed frequently discussed barriers over the course of treatment, with discussions often skewing negatively. The barriers expressed by users differed somewhat for black and Hispanic users compared with white users and were more often related to preferences, perceptions and cultural/religious/spiritual beliefs, costs of therapy, and logistical barriers.

Racial disparities in breast cancer are well documented and the reasons for treatment differences and outcomes are complex [3–5, 7, 23, 29–38]. Not surprisingly, our findings have suggested similar themes in barriers to care as raised by others in the literature, including access [7, 10–12], system failures [23], mistrust of providers [4], and psychological issues [39–41]. However, some of our findings should be highlighted. Misperceptions, healthcare preferences, and spiritual/cultural/religious beliefs comprised nearly one quarter of the barriers to treatment reported in our study, with physical barriers such as side effects comprising <10 % of posts by black and Hispanic women and only 18 % overall, although we were unable to fully assess whether treatments were not completed or not initiated at all. Further, modifiable factors such as resource barriers were frequently reported by users, and among

Table 1 Representative quotes from each barrier type identified*

Specific barrier	Representative quotes
Emotional (<i>n</i> = 89,064)	
Anxiety (29 %)	I get my results tomorrow too. I'm getting more anxious by the minute
Fears (35 %)	I am so afraid that I could cry
Denial (13 %)	I have no time for potential troubles, having enough actual ones
Depression (23 %)	I've never been this depressed in my life. I really don't know where to begin
Beliefs (<i>n</i> = 81,319)	
Misperceptions (29 %)	Breast cancer does not run in my family so I am not at risk
Healthcare preferences (30 %)	We don't go to the doctor until we're very sick
Spiritual/religious/cultural (41 %)	Whatever our religious beliefs, if you believe in a great Creator, this is the part of the plan and my plan for health Breast cancer is a white woman's disease
Physical (<i>n</i> = 69,702)	
Side effects (40 %)	The digestive effects of this chemo are horrid
Limitations (31 %)	Breast cancer treatment just destroys the body? It feels like it will is simply not possible to ever regain any fitness once you've lost it?
Body change (29 %)	My hair is becoming so thin and going away I won't feel like a whole woman anymore
Resources (<i>n</i> = 58,085)	
Insurance (49 %)	I have no insurance and have just been diagnosed. What are my options?
Costs (33 %)	I'm not sure I can afford to have breast cancer. With the hormones and all the meds, I'm gonna go broke
Logistics (18 %)	I only have access to public transportation and it's so hard to coordinate all my appointments I don't always have someone to watch their kids when they go in for an appointment
Healthcare perceptions (<i>n</i> = 34,851)	
Poor communication (36 %)	My oncologist doesn't tell me anything. I get most of the important info and instruction from his RN
Negative experiences (21 %)	They were rude the whole time, made me feel ignorant and I am not sure I want to proceed with it!! I had my doctor switched to a woman doctor so I wouldn't be as embarrassed or feeling violated
Trust (22 %)	I don't 'trust' doctors anymore, but am confident my current care team is competent. My last one wasn't. If you have doubts go elsewhere, preferably a cancer center
Accessibility of services (21 %)	The doctor's office is so far away and inconvenient, it's almost impossible for me to get there
Relationships (<i>n</i> = 27,106)	
Intimacy (35 %)	...it saddens me that there are men out there who cannot support their wives through this terrible ordeal
Friends (34 %)	A life changing diagnosis of breast cancer has shown me who my friends are and who I can count on in my life
Children (31 %)	(This has) caused feelings of worry and guilt about my role as a mother
Duration/process (<i>n</i> = 26,987)	
Regime (41 %)	I had 33 rads, 28 reg and 5 boosts. I took a 10 break for vacation about mid-way through but still was tired
Duration of treatment (23 %)	I'm not sure if I can handle this anxiety for results for five more years
Aftereffects (19 %)	I just can't take the time off...I'm afraid I'm going to lose my job. It's my life and I need it
Complexity (17 %)	My cancer treatment didn't come easily...it involved of a complex series of treatments and was a very difficult process

* *n*'s represent the numbers of unique posts expressing these sentiments

users reporting not receiving treatment for their breast cancer, preferences/perceptions and religious/cultural/spiritual beliefs, worry about side effects, denial, and fatalism were the most commonly reported barriers. Further,

organizational barriers were more frequently discussed by minority (vs. white) users during pre-diagnosis and diagnosis, suggesting obstacles with system factors. All of these findings suggest that tolerability of treatments is not a

predominant issue limiting treatment receipt and that addressing beliefs and logistical barriers has potential to impact receipt of care. These mutable factors should be surmountable with the right patient education, support, and services for patients (e.g., navigators, coordinators, patient assistance funds).

Using this type of ‘social intelligence’ for research is a new, iterative research discipline that mines the vast repository of unstructured big data for insight into patients’ concerns and experiences. It does not rely on pre-defined content or rules-based programming and is instead driven by pattern recognition and adaptability to thematic content. In contrast, conventional research methods are more structured and work to formalize relationships between variables, providing robust tests for statistical significance. Further, traditional research methods typically rely on model assumptions and have the risk of suggesting the wrong study conclusions if the underlying assumptions are wrong.

Finding ways to optimally capitalize on the immense power of online candid patient interactions and conversations provides a new method of conducting qualitative and eventually quantitative research across many medical disciplines. Here, we captured spontaneous, real-time conversations in a non-intrusive way and in a natural setting. Further, we included over 50,000 posts from users who self-identified as black or Hispanic, representing a substantial proportion of the posts analyzed in our analysis, and demonstrating the ability to reach diverse users with this type of research. Social media represents an essentially untapped resource of big data with vast potential, particularly in patients who are difficult to reach using traditional methods. In particular, this type of research may prove optimal when examining the late and longer-term impact of our treatments among cancer survivors, when active clinical follow-up becomes more limited.

Despite the novel and exciting nature of this research, we recognize several challenges with this type of analysis. First, we lacked demographic information on many users, and although race/ethnicity was self-reported, it is possible that we misclassified some users. Second, although we focused search terms on treatments administered for curative intent, we could not distinguish metastatic from non-metastatic users. However, understanding barriers to treatment regardless of cancer stage is important. Third, the views expressed online may be skewed negatively because struggling patients may be more likely to engage in a community for support, although these may be the patients who are most important to reach with this type of study. In addition, the feelings expressed by a social media user may be ‘different’ from those expressed in other situations (e.g., at an office visit with a provider), but may not necessarily be more representative of the truth for that patient. Fourth,

it is possible that some users posted within multiple different conversation threads, and although multiple posts within a single discussion/conversation by a user were only included once, some users may have posted on various discussions or sites. Fifth, we had no information on specific treatments recommended or treatment adherence.

In conclusion, we harnessed real-world data using this novel modality for qualitative research, capitalizing on the rich conversations occurring online for patients with breast cancer. We learned about barriers to care for a large and diverse population of users and will use these data to inform an upcoming survey to further explore the issues identified. We observed a smaller than expected proportion of users reporting physical barriers to treatment as a limiting factor, while modifiable factors such as resource, organizational, trust, and beliefs about treatment were more predominant. Future research should further focus on how to further employ and learn from this type of social intelligence research.

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Compliance with ethical standards

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