Identifying the principal drivers of heightened anxiety during breast cancer diagnosis through the analysis of social media data on Reddit: mixed methods study

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Abstract

Background: More than 85% of patients report heightened levels of anxiety following cancer diagnosis. Anxiety can become amplified during the early stages of the breast cancer diagnosis process when ambiguity is high. High levels of anxiety can negatively impact patients by reducing their ability to function physically, make decisions, and adhere to treatment plans, with all these elements combined serving to diminish the quality of life.

Objective: Using individual social media posts about breast cancer experiences from reddit.com (r/breastcancer), we aim to understand the dimensions of cancer-related anxiety as individuals move from suspecting to confirming cancer diagnosis.

Methods: Our team coded the entire corpus of 2,170 unique posts from r/breastcancer with respect to key variables, including whether the post was related to prediagnosis, diagnosis, or postdiagnosis concerns. We then used Linguistic Inquiry and Word Count (LIWC) to rank-order the codified posts as low-, neutral- or high-anxiety. High-anxiety posts were then retained for deep qualitative analysis to identify key themes relative to diagnostic progression.

Results: After several iterations of data analysis and classification through both qualitative and computational methods, we identified a total of 448 high-anxiety posts across the three diagnosis categories. Our analyses revealed that individuals experience higher anxiety before a confirmed cancer diagnosis. Analysis of the high-anxiety posts revealed that the drivers of anxiety differed depending on an individual's stage in the diagnostic process. Prediagnosis anxiety was driven by physical symptoms, cancer-related risk factors, and difficulty navigating the healthcare system. During the diagnosis period, high anxiety was associated with physical symptoms, cancer-related risk factors, and unclear communication. Following diagnosis, high anxiety posts generally discussed topics related to treatment options, understanding medical reports, or financial or other logistical issues.

Conclusions: This study has practical, theoretical, and methodological implications for cancer research. Content analysis reveals the key drivers of anxiety at each stage (pre-, during, and postdiagnosis) and provides key insights into how clinicians can help alleviate anxiety at all stages of diagnosis. Findings provide insights into cancer-related anxiety as a process beginning prior to engagement with the healthcare system: when an individual first notices possible cancer symptoms.

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Title: Identifying the principal drivers of heightened anxiety during breast cancer diagnosis through the analysis of social media data on Reddit: mixed methods study

ABSTRACT

Background: More than 85% of patients report heightened levels of anxiety following cancer diagnosis. Anxiety can become amplified during the early stages of the breast cancer diagnosis process when ambiguity is high. High levels of anxiety can negatively impact patients by reducing their ability to function physically, make decisions, and adhere to treatment plans, with all these elements combined serving to diminish quality of life.

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communication. Following diagnosis, high anxiety posts generally discussed topics related to treatment options, understanding medical reports or financial or other logistical issues.

Conclusions: This study has practical, theoretical, and methodological implications for cancer research. Content analysis reveals the key drivers of anxiety at each stage (pre-, during, and postdiagnosis) and provides key insights into how clinicians can help to alleviate anxiety at all stages of diagnosis. Findings provide insights into cancer-related anxiety *as a process* beginning prior to engagement with the healthcare system: when an individual first notices possible cancer symptoms.

Implications for Cancer Survivors: Uncertainty around physical symptoms and risk factors suggests the need for increased education and improved access to trained medical staff that can assist patients with questions and concerns during the diagnostic process. Assistance in understanding technical reports, scheduling, and patient-centric clinician behavior may pinpoint opportunities for improved communication between patients and providers.

Keywords: Breast cancer, anxiety, social media

In 2020, more than 2.3 million women worldwide were diagnosed with breast cancer and over 685,000 died from the disease. Every 14 seconds a woman is diagnosed with breast cancer worldwide, and in the US someone is diagnosed every 2 minutes. Breast cancer is the most common cancer diagnosis in 140 of 184 countries worldwide. In the US, it is the most common cancer after nonmelanoma skin cancer. Research has demonstrated that breast cancer diagnosis is associated with an increase in anxiety surrounding self-concept, mortality, cancer recurrence, treatment, and altered body image [1,2] [3–5]. Furthermore, increased anxiety is associated with impaired physical functioning, reduced quality of life, decision making ability, delayed return to work and poor adherence to treatment [6]. Yet for many, anxiety has its roots much earlier in the process of a cancer diagnosis, specifically when an individual first notices physical changes or risk factors that may represent an increased risk of cancer diagnosis [6,7] . Researchers have largely acknowledged increased anxiety following diagnosis [8] [9], but less research has explored the anxiety associated with suspecting one may have breast cancer [10]. Untreated anxiety increases and amplifies the emotional and physical suffering of breast cancer patients. By increading understanding of the relationship between anxiety and breast cancer, clinicians can provide more advance interventional care to support better overall patient well-being. Advancing the scientific understanding of the ways that individuals experience anxiety during the different stages of cancer diagnosis, including the very early stages when breast cancer is suspected rather than officially diagnosed, provides an opportunity to support whole person care. By connecting and co-treating breast cancer diagnostics and elevated anxiety, clinicians are better able to manage the process of adverse health diagnoses with mental health outcomes. Considering the ways

these two health processes interact allows clinicians to provide appropriate support for an individual's mental health as they proactively seek medical treatment.

Evaluating mental health outcomes like anxiety, *after* an individual suspects disease but *before* they have received a diagnosis, requires specific types of data capable of providing insight into each individual person's dynamic mental and physical health status over a very specific time-period related to the diagnosis. Time-varying, individual-level data capable of capturing the linkages between these processes is rarely, if ever, collected in studies of breast cancer and anxiety because it requires information about individuals based only on a suspicion of disease rather than a medical diagnosis. The goal of this study is to explore anxiety, with specific attention to the drivers of anxiety, across the diagnostic continuum during breast cancer diagnosis. To conduct this research we design a unique data set derived from social media posts and analyzed and interpreted through a qualitative lens. We collected data from the Reddit community r/breastcancer. Reddit.com is a social media platform that focuses upon community engagement by offering sub-communities – known as *subreddits* -- of specific areas of interest, like breast cancer. Reddit has over 1 billion registered users with 47% of active users being in the US [11]. We analyzed all thread-initiating posts from the r/breastcancer Subreddit. We began by qualitatively assessing all posts to determine at what stage in the diagnostic process the original poster (OP) is. We then used computational methods to identify posts characterized by high relative frequency of anxiety-related terms. The "high-anxiety" posts were then retained for close qualitative analysis to determine key themes that could provide insight into the drivers of anxiety - and to qualitatively assess whether those topics differ based on the individual's stage in the diagnostic process.

Theoretical Framing

Research has shown that up to 85% of breast cancer patients experience elevated rates of anxiety related to changes in body image and sexual functioning, new responsibilities regarding treatment and treatment management, personal relationships, and logistical and financial concerns. Anxiety levels can be categorized as "state anxiety" meaning the anxiety is associated with a condition or situation whereas "trait anxiety" is the propensity to worry and experience fear on a regular basis. 45% of patients reported severe state anxiety in the early stages of breast cancer diagnostics and treatment [7]. These heightened levels of anxiety can result in a host of adverse mental and physical health outcomes alongside diminished quality of life, potentially negatively impacting both immune response and cognitive functioning [12,13].

While nearly all breast cancer patients experience some anxiety surrounding diagnosis, research has identified risk factors that have been shown to exacerbate anxiety among breast cancer patients [2,14]. These risk factors can be divided into four distinct categories: (1) staging and cancer progression, (2) mental health history, (3) physical symptoms,

and (4) patient (demographic) characteristics. Research on *staging and cancer progression* shows higher levels of anxiety for individuals diagnosed with metastatic breast cancer [14] [15], while *mental health predictors* include a prediagnosis history of diagnosed anxiety or depression [1,14,16–19] or a pre-cancer history of diagnosed personality disorder [16]. *Physical symptoms*, including pain, fatigue, insomnia, digestive disorders, and mobility issues were associated with elevated anxiety levels during treatment and up to 12-months following treatment completion [3,8,20]. Patient or demographic characteristics including age and race were also shown to impact anxiety levels both directly and indirectly [17,20–24].

The preponderance of research on breast cancer-related anxiety has focused on anxiety following cancer diagnosis. This postdiagnosis focus encourages a unilateral conceptualization of anxiety. Specifically, unlike trait anxiety, state anxiety is a transitory emotional state that depends on a host of context-level factors (Leal et al., 2017). These context-level factors change as an individual moves from suspecting to confirming breast cancer diagnosis. These changes are associated with disruption and ambiguity and lead to heightened levels of anxiety (Hirsch et al., 2012). More to the point, evidence suggests that cancer-related anxiety does not emerge at time of diagnosis [10]. For example, [25] showed spikes in cancer-related anxiety associated with abnormal and potentially problematic breast cancer screenings. Further, research exists to support the notion that not only do cancer-related anxieties first emerge prior to cancer diagnosis, but that those anxieties may diminish in the aftermath of a confirmed diagnosis [26]. Taken together, these studies suggest that anxiety has roots much earlier in the diagnostic process and evolves as patients encounter new challenges and gather new information.

Breast cancer related anxiety and social media support

We collect data from reddit.com, a virtual space where many users find support through sharing their testimonials and asking for advice. Social support has been shown to be an effective tool to help people cope with anxiety. The transfer of advice, resources and information in response to a stressor has been shown to reduce anxiety and to buffer against the deleterious effects of stress through a variety of mechanisms and in a variety of contexts (for a broader discussion see e.g., [27–30]. Despite this, changes in support needs often coincide with moments of limited support availability [31]. In light of this, many individuals have turned to breast cancer support networks created and maintained online. Often associated with benefits similar to those of face-to-face social support exchange, computer-mediated social support, like that potentially offered through Reddit, offers notable advantages in the transmission of social support, including anonymity [32], improved congruence between the nature of support sought and support received [33], reduced communication barriers [34], and increased agency in support seeking [35].

Support seeking in the context of online communities provides unique data opportunities for using automated

text processing methods to measure the relative levels of anxiety among individuals at different stages of their breast cancer diagnosis journey and to identify high anxiety posts for subsequent qualitative analysis. Combining qualitative and computational methods, this paper reconstructs a diagnostic timeline to examine the evolution of anxiety beginning when an individual first suspects breast cancer. We then use qualitative analysis to identify the key drivers of anxiety and how those drivers shift prior to, during and following cancer diagnosis. Our mixed, computational-qualitative analysis is designed to provide insights into the factors exacerbating anxiety among individuals suspecting breast cancer and to observe how those factors evolve through the diagnostic and treatment processes.

Methods

The objective of this study was to determine the principal contributors to anxiety among individuals suspecting breast cancer. Relying on reddit.com's broad and diverse user base, we extract breast cancer and anxiety data from the r/ breastcancer subreddit, a community for individuals who suspect or have been diagnosed with breast cancer (or are supporting someone who has). To analyze the data, we developed a multi-stage process reliant on text analytics methods, specifically we utilized an anxiety lexicon derived from the Linguistic Inquiry and Word Count tool (LIWC) to automatically identify those posts in our dataset that manifested high anxiety (i.e. contained a relatively high proportion of anxiety-related words), then we performed a qualitative analysis focusing specifically on the "high anxiety" posts identified by LIWC [36]. The analysis consisted of three phases: (1) initial qualitative analysis to perform codification and classification of cancer-related posts into chronological categories – prediagnosis, diagnosis, and postdiagnosis, (2) LIWC analysis was used to identify three different levels of anxiety among the posts – low, medium, and high; and lastly (3) a deep qualitative analysis of the high anxiety posts to identify principal drivers to anxiety and the changes to drivers of anxiety as an individual moves from the prediagnosis stage to confirmation of cancer diagnosis. The analysis procedures and associated phases are depicted in Figure 1 and each phase is discussed in greater detail, see Additional file 1.

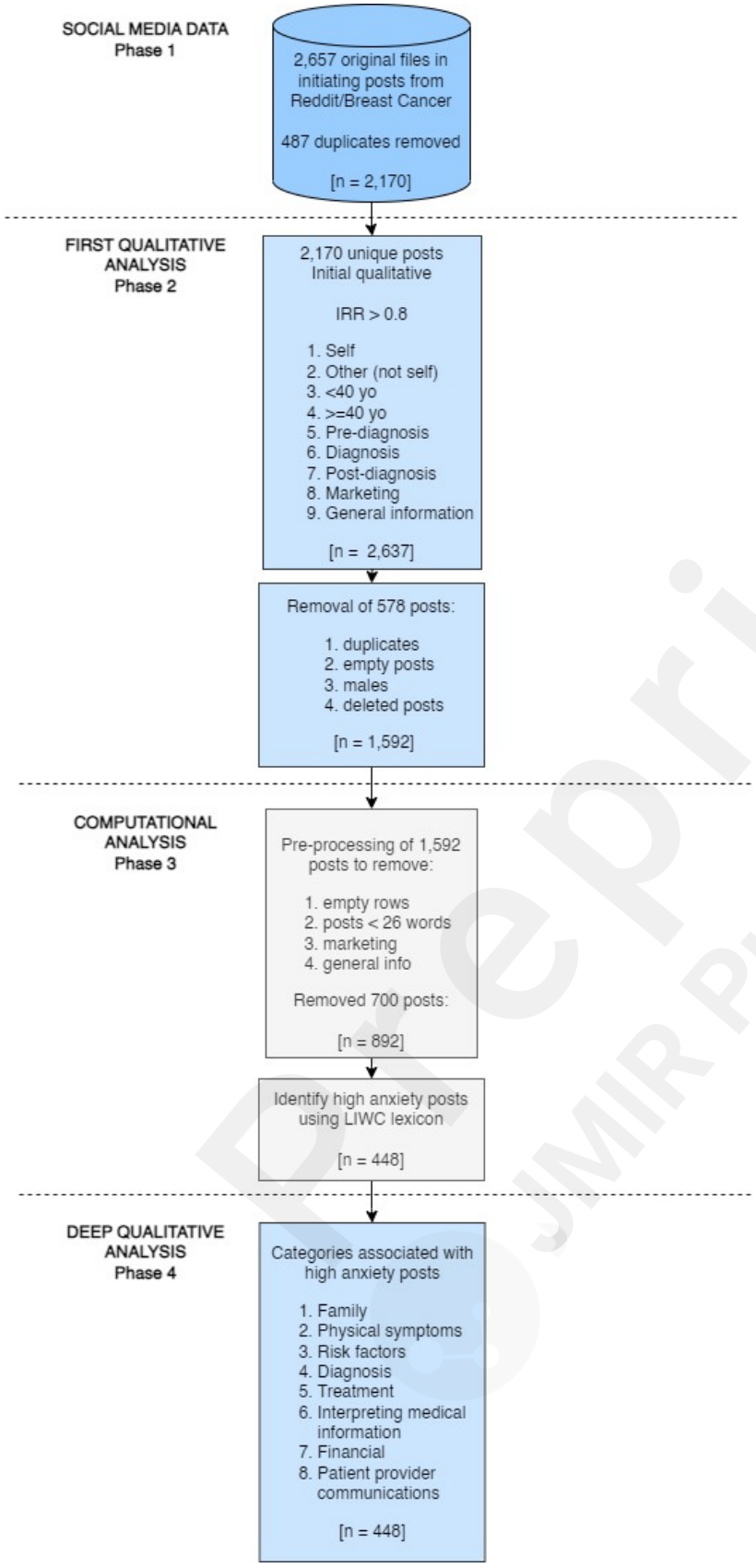

Figure 1. Multi-phase analytic approach

(1) ***Classification***

Given our interest in anxiety and its drivers, we focused on initiating posts; or posts that propose a topic or question

to which users can respond. Using the PushShift Application Programming Interface (API), we collected all initiating posts from reddit.com's r/breastcancer subreddit. This yielded a total dataset of 2,170 posts. Authors JM, JP and MC evaluated all posts following a bottom-up coding technique, identifying broad content classifications that were likely to impact the degree and nature of anxiety expressed in the online posts. Authors then met weekly to consolidate and collapse categories.

Bottom-up Inductive analysis revealed three dimensions most likely to impact the degree and cause of individuals' anxiety: (1) whether an individual had a confirmed breast cancer diagnosis, (2) the age of the users, and (3) whether an individual was posting about ***their own*** or ***another person's*** cancer diagnosis. Two subsequent categories also emerged with considerable overlap between them: general information posts and advertisements. General information posts were posts that included general information about breast cancer, cancer treatment or risk factors; where advertisements included any solicitation of cancer patients, from products and services to scientific studies. As general information and advertisement posts were often generated by bots or individuals other than those suspecting breast cancer, these posts were excluded from final tabulation and analysis. In all, 1,592 posts were retained for analysis.

The final coding classification scheme had nine dichotomous categories: (1) identification of breast cancer risk (prediagnosis), (2) engagement with medical practitioners to confirm breast cancer diagnosis (diagnosis), (3) confirmed breast cancer diagnosis (postdiagnosis), (4) under 40 years old, (5) over 40 years old, (6) posting about own breast cancer, (7) posting about another's breast cancer, (8) general information about breast cancer, and (9) advertisements. After removing all posts for general information and advertisements we retained seven final classification categories shown in Table 1.

Table 1: Initial Classification of Reddit Posts

Category	Variable Type	Description
Self	y/n	OP discusses own cancer risk / diagnosis
Other	y/n	OP discusses some else's cancer risk / diagnosis
Under 40	y/n	OP reported age under 40
Over 40	y/n	OP reported age over 40 / did not report age
Pre-dx	y/n	Post refers to events or concerns that occur *prior to* seeking medical attention
Dx	y/n	Post refers to concerns during / resulting from engagement with the medical system while seeking out diagnosis
Post-Dx	y/n	Post refers to events or concerns following formal diagnosis

To quantify agreement between coders, we utilized Cohen's kappa. After three rounds of annotation (coders MC, JP, JM) we achieved an agreement score of 0.81. Cohen's kappa > 0.7 is generally considered acceptable agreement [37].

(2) Computational analysis using natural language processing (NLP)

After the initial classification into the coding categories described above (self, other, age, etc.) and the exclusion of

posts that were duplicates, empty posts, and deleted posts. We used an automated text analytics method to assign an anxiety score to all 1,592 posts (i.e. a score that indicates the extent to which a particular comment exhibited anxiety). To achieve this, we used lexicons derived from the Linguistic Inquiry and Word Count (LIWC) 2007 lexicon [36], [38], a widely used resource [39], [40], [41] that automatically quantifies the presence of salient psychological categories from text (e.g. positive affect, negative affect, cognitive processes, perceptual processes, swearing).

In the context of social media analysis, LIWC lexicons have been used extensively to study the emotional and cognitive consequences of various scenarios including 1) romantic breakup [42], 2) studying expressions of loneliness [43], and most salient to our current research question, 3) to study emotional expression in cancer survivors [44]. A key feature of LIWC that makes it well-suited to our goal is the fact that *anxiety* is among the 63 psychological dimensions encoded in LIWC. The *anxiety* category consists of 91 terms (e.g. *alarm**, *asham**, *uneas**) that can be used to quantify the extent to which a given text exhibits anxiety. Note that the asterisk is a wildcard that allows the pattern to match relevant derivational and inflectional morphemes (e.g. the pattern *alarm** will match “alarm”, “alarmed”, and “alarming”).

We used the LIWC anxiety lexicon in conjunction with the Python text processing library, the Natural Language Toolkit [45]. We used the Natural Language Toolkit to first tokenize each comment into its constituent word tokens, then (programmatically) counted the number of words in each post that matched a term in the LIWC anxiety lexicon. We excluded posts relating to marketing and general discussion of breast cancer issues, as in this research we are primarily interested in the lived experience of Reddit users experiencing breast cancer. From our starting point of 1,592 posts, these preprocessing steps led to a final data set of 892 posts.

We calculated anxiety scores to distinguish high-anxiety posts from low-anxiety posts. Anxiety scores were determined by first calculating the normalized frequency of LIWC anxiety terms per post expressed as a percentage. This approach accounts for the fact that posts varied in length. Next, we calculated the median percentage across the 892 posts and then converted the percentage to an ordinal variable (i.e., 0 [NONE] - no LIWC terms; 1 [LOW ANXIETY] = percentage > 0 but less than the median percentage; and 2 [HIGH ANXIETY] = percentage >/= median value). Table 2 shows frequency counts for each category.

Table 2. Ordinal Values

Breakdown of Ordinal Variables	Score	Count
No anxiety	0	336
Low anxiety	1	108
High anxiety	2	448

(3) Qualitative analysis of high anxiety post themes

The computational analysis and codification described in step 2 began with the analysis of 1,592 posts. We removed 578 posts due to duplicates, empty posts and deleted posts which yielded a subset of 892 posts. Of those, 448 posts were categorize as high anxiety posts across (1) diagnostic stage, (2) patient age, and (3) self vs. other. To account for multiple categorizations for a single post, we created three separate datasets for prediagnosis concerns, concerns surrounding diagnosis and care engagement, and concerns that emerged after a confirmed breast cancer diagnosis.

Posts were once again analyzed using a bottom-up, constant comparison approach. Authors JM and JP immersed themselves in the datasets to identify what social media data reveals about the sources of anxieties among individuals suspecting breast cancer, along with factors that may exacerbate cancer-related anxiety, and how those anxieties may evolve between an individual's discovery of cancer risk, through testing to eventual diagnosis.

Authors JM and JP independently coded 50 posts from each of the three datasets and met weekly to identify emerging themes with the goal of identifying the array of themes that captured the largest number of original posts across all three of the data sets. Once authors had completed the original coding of the first 150 posts, we met to consolidate and collapse themes. The final list of themes is presented in Table 3, below.

Once the final list of anxiety categories had been established, authors JM and JP divided the remaining 448 posts between them. Tabulating mentions of each of the anxiety types mentioned in Table 3 to track the frequency of each within and between each of the diagnostic stages: prediagnosis, diagnosis, and postdiagnosis. Authors also conducted a close reading to identify factors that may exacerbate anxiety or how anxiety is likely to evolve over time. Results of the computational analysis, tabulation, and qualitative analyses are presented in text and table form in the results section, below.

Results

Our cross-sectional analysis of anxiety among individuals suspecting breast cancer as they move from suspecting to screening for and eventually confirming a breast cancer diagnosis consisted of a three-phase analysis plan: from (1) classification, (2) computational analysis of linguistic markers, and (3) deep detailed qualitative analysis of anxiety in social media posts. Results are organized according to these methods.

(1) ***Classification***

Our first-round classification of the entire r/breastcancer subreddit (i.e. 1,592 original initiating posts) yielded three principal classification categories: (1) an individual's stage in the diagnostic process (i.e. prediagnosis, diagnosis or postdiagnosis) (2) an individual's age (i.e. over / under 40), and (3) whether the post related to the poster's own cancer experience or that of a loved one. Tabulations can be found in Table 3.

Table 3. Principle Classification Categories

Diagnostic Stage		**Patient Age**		**Person**	
Prediagnosis	235	Under 40	298	Self	539
Diagnosis	185	40 and over	594	Other	353
Postdiagnosis	352				

(2) ***Computational Analysis***

Of the 892 initiating posts that remained after the pre-processing steps in phase 3 shown in figure 1, 336 were classified as having no evidence of anxiety, 108 were classified as low anxiety, and the remaining 448 were classified as high anxiety. Posts varied in length with a mean number of words of 193 (median 152; range 26-1766). Our analysis (see additional file 1) revealed that anxiety was substantially higher for younger individuals, individuals posting about their own cancer diagnosis, and individuals in the prediagnosis and screening phases of cancer diagnosis. See Table 4 for descriptive statistics.

Table 4. Descriptive Statistics

Category	**% (n) posts**	**Median anxiety score**	**Most common anxiety terms**
All	100 (892)	2 (high anxiety)	worried, scared, risk, worry, anxiety
< 40 years of age	33.4 (298)	2 (high anxiety)	Worried, scared, risk, worry, anxiety
>= 40 years of age	66.6 (594)	1 (low anxiety)	Worried, scared, risk, anxiety, worry
Self	60.4 (539)	2 (high anxiety)	Worried, scared, risk, anxiety, worry
Other	31.8 (284)	1 (low anxiety)	Worried, scared, worry, afraid, fear
Prediagnosis	26.3 (235)	2 (high anxiety)	Scared, worried, risk, anxiety, worried
Diagnosis	20.7 (185)	2 (high anxiety)	Scared, worried, worry, anxiety, nervous
Postdiagnosis	39.5 (352)	1 (low anxiety)	Worried, scared, risk, anxiety, worry

(3) ***Qualitative analysis of high anxiety post themes***

General inductive analysis revealed nine themes associated with high anxiety posts (Table 5). While research on cancer and anxiety has typically focused on the stresses faced by breast cancer patients following diagnosis, our results provide compelling evidence that not only does anxiety have its roots much earlier in the diagnostic process, but that anxiety manifests differently based on whether an individual is first discovering breast cancer risk, engaging with the

medical system, or have already received a formal breast cancer diagnosis. Our findings also suggest that those risks may change as individuals move from one diagnostic group to the next.

General inductive analysis revealed nine key themes (see Table 5). Themes centered around either (1) an original identification of elevated cancer risks (***physical symptoms, risk factors)***, (2) navigating the bureaucracy of the health system (***diagnosis, treatment, interpreting medical information),*** (3) logistic toxicity (***financial),*** understanding or communicating with providers ***(patient provider communication)***, or managing emotional distress ***(family, emotional distress).***

Table 5: Qualitative Themes from High Anxiety Posts

Anxiety Theme	**Definition**
Family	Refers to impact of potential diagnosis on children / family, preparation for life postdiagnosis / post-cancer, communicating diagnosis / health concerns
Physical Symptoms	Physical symptoms concerns indicating cancer, cancer type, or gravity
Risk Factors	Concerns regarding family history, lifestyle, genetic predisposition or carcinogenic exposure
Diagnosis	Issues with diagnosis, missed diagnosis, persistent symptoms, or inconclusive initial test results
Treatment	Questions regarding treatment, treatment decisions, or side effects
Interpreting Medical Info	Anxiety resulting from online research and Google searches. Difficulty in understanding/interpreting medical reports or lab reports. Interpreting clinician behavior.
Financial	Concerns regarding insurance, treatment costs, or costs of tests. Job-related issues.
Patient Provider Communication	Confusion / anxiety resulting from engagement with healthcare staff, clinicians
Emotional Distress	Difficulty in managing emotions. Fear that emotions were interfering with daily functioning or thinking clearly.

Characteristics of the three phases *(prediagnosis, diagnosis, postdiagnosis)* are listed in Tables 6-8, below. The tables show a clear evolution of cancer concerns. Prediagnosis concerns across age categories (over and under 40) tended to focus primarily on physical symptoms and risk factors. Notably, 65 of the 78 *self / under 40* posts included mention of physical symptoms, while 44 of the 53 *self / over 40* posts included mention of changes in physical symptoms. A significant number of posts also focused on healthcare engagement. Healthcare engagement posts often included requests for information about how, when, and from whom to seek care for marked physical changes.

Table 6. Prediagnosis Data

Breast Cancer & Social Media	**Prediagnosis**			
	Self (n=131)		Other (n=14)	
Anxiety Related Categories	<40 yo (n=78)	40+ yo (n=53)	<40 yo (n=78)	40+ yo (n=53)
Family	3	4	0	0

Physical symptoms	65	44	3	7
Risk factors	30	22	1	3
Diagnosis	2	3	2	5
Treatment	3	3	0	1
Interpreting medical information	7	4	1	4
Financial	2	3	0	0
Patient provider communication	12	4	1	3
Emotional distress	5	3	2	0

Moving from Table 6 to Table 7, incidence of physical symptoms and risk-related anxiety remains very high. However, a closer read of the post content reveals that physical symptoms or risk factor discussions tended to present physical symptoms and risk factors primarily as a backdrop to more specific questions about treatment, financial distress or issues with the healthcare engagement process.

During the diagnostic process, individuals tended to report more anxieties stemming from either ***patient provider communication*** or ***interpreting medical information.*** Anxiety stemming from ***patient provider communication*** frequently resulted from individuals' own attempts to reduce ambiguity by gleaning additional information from clinician behaviors. Posters noted specific instances where technicians interrupted screenings and left the room. Posters also reported being contacted by clinic staff to move up an appointment date. When clinicians did not provide additional information, posters often interpreted these behaviors as indicating a potential problem.

Interpreting medical information might include either instances where individuals were unable to decipher complex medical reports or cases in which individuals took to the Internet to research their own symptoms. In one instance, an adolescent posted that he needed help translating a medical report for an English-language learning parent who had been provided screening results in English.

Table 7. Diagnosis Data

Breast Cancer & Social Media	**Diagnosis**			
	Self (n=92)		Other (n=12)	
Anxiety Related Categories	<40 yo (n=48)	40+ yo (n=44)	<40 yo (n=4)	40+ yo (n=8)
Family	6	0	0	0
Physical symptoms	42	29	4	6
Risk factors	20	7	2	1
Diagnosis	9	9	2	1
Treatment	1	1	1	2
Interpreting medical information	19	5	0	1
Financial	4	2	0	0
Patient provider communication	15	16	0	0
Emotional distress	4	3	0	0

There are several notable changes in content themes in the postdiagnosis table, Table 8. Following diagnosis, individuals were significantly less likely to report on physical changes and risk factors that were dominant themes in the

prediagnosis and diagnosis tables. Rather, anxious posts about an individual's own cancer tended to focus on issues related to treatment, most notably in the under 40 group. These individuals were often seeking advice from individuals who had been through cancer diagnosis and treatment, and could provide insights related to cancer treatment, treatment side-effects, or reconstructive surgery.

Another marked shift that occurred in the postdiagnosis table was a shift in the proportion of posts about one's own cancer. In the prediagnosis and diagnosis datasets, most of the high anxiety posts were from individuals suspecting they may have breast cancer. These were individuals who were, themselves, seeking a breast cancer diagnosis, at n = 14 (10% of pre-dx posts) and n = 12 (12% of diagnosis posts). The postdiagnosis group was characterized by a significantly larger proportion of high anxiety posts originating from someone other than the person with breast cancer (n = 85, or 55% of posts).

Table 8. Postdiagnosis Data

Breast Cancer & Social Media	**Postdiagnosis**			
	Self (n=70)		Other (n=85)	
Anxiety Related Categories	<40 yo (n=29)	40+ yo (n=41)	<40 yo (n=7)	40+ yo (n=78)
Family	14	8	3	4
Physical symptoms	5	12	2	8
Risk factors	4	4	1	5
Diagnosis	3	6	0	10
Treatment	14	24	5	27
Interpreting medical information	3	2	1	18
Financial	1	3	1	5
Patient provider communication	1	5	1	1
Emotional distress	4	8	1	5

Discussion

The goal of this study was to understand the nature and evolution of anxiety faced by individuals suspecting breast cancer as they move from discovery of cancer risk to engagement with the medical system and cancer screenings to eventual cancer diagnosis. To do this, we downloaded, codified, and categorized the entire corpus of posts from the r/breastcancer subreddit. We then used computational analysis tools to give each post an ordinal anxiety score. Next, we looked qualitatively at the content of posts identified as "high anxiety" to understand the drivers of anxiety, and how those drivers differed based on the stages at which an individual was in the diagnostic process. This provided insights into how drivers of anxiety may shift as individuals' circumstances and cancer risks change.

Our qualitative analysis and post tabulations provide key insights into how anxiety manifests in each of the diagnostic phases: prediagnosis, diagnosis, and postdiagnosis. Notably, our results indicate a need for additional public information regarding early breast cancer warning signs. Many of the high anxiety prediagnosis posts stemmed from changes in physical symptoms or identification of new family or behavioral risk factors. Nearly all users participated in

the breast cancer subreddit community to assess their likelihood of a breast cancer diagnosis based on the physical symptoms and risk factors they identified in their original post. Several sought advice about whether the physical symptoms they described merited medical attention, cancer screenings, or where to seek treatment. Others who discovered risk factors were unclear what should be done once they became aware of a high likelihood of a subsequent cancer diagnosis.

Results also pointed to the potential for improvements in patient / provider communication. For example, in addition to direct reports of feeling mistreated or dismissed by clinic staff, informational ambiguity emerged as a major source of anxiety. High anxiety posts were often related to difficulties understanding complex medical reports or understanding clinic or clinician behaviors (e.g., leaving appointments mid-screening to find an oncologist, scheduling of follow-up appointments, or even moving previously scheduled appointments). Furthermore, many individuals used websites like WebMD or Google to try to understand medical reports, physical symptoms, risk factors, or the behavior of their clinician or clinical staff, but results of independent and unguided searches often contributed to individuals' anxiety and ended up reported in patient posts as drivers of anxiety.

Numerical and qualitative results are also highly suggestive that anxiety be viewed as a process, and that risk of high anxiety is actually higher before breast cancer is diagnosed. While we look at a cross-section of data between individuals, our results show a clear evolution in the primary drivers of anxiety based on an individual's staging within the diagnostic process.

There was also a marked shift in the postdiagnosis table. In the prediagnosis and diagnosis groups, most of the original posters were individuals who were concerned about their own cancer. In the postdiagnosis table, over half of posts came from individuals worried about the possible diagnosis of a close friend or family member. This shift may highlight the need for additional formal support structures for friends and family of cancer patients. The corresponding drop in the number of posts from cancer patients may be an artifact of the more formal structures in place to provide support to individuals as they cope with treatment decisions, including social workers, nurses and practitioners as well as websites such as PatientsLikeMe.com. These structures and friendships may not be in place for individuals coping with the breast cancer of a loved one. The subreddit sites may provide invaluable secondary support, however they may also signal the need for more formal networks of support and support groups for individuals providing care and support to a cancer patient.

Limitations

By looking at individuals in different phases of the process we were able to obtain a good sense of what the evolution of stress might look like as individuals move from suspicion to confirmation of breast cancer. This approach

may be advantageous, in that our dataset includes the concerns of individuals who are ultimately NOT diagnosed with cancer. That said, our study does not include longitudinal data and therefore can only suggest a possible evolutionary trajectory associated with anxiety, rather than providing a map.

Our data is also not representative of breast cancer patients, more generally. Contributors to health-related discussion platforms are estimated to represent only a small proportion of overall users. In a study of 63,990 social media users, van Mierlo found that 90% of users were silent observers or "*lurkers"* rather than active participants. [46]. Nine percent of users contributed sparingly and only 1% were actively engaged in online dialogue. We estimate some derivative of these ratios translates to the r/breastcancer subreddit thus limiting representation of the full range of views in this community.

Conclusions

The significance of this study is the identification of high anxiety drivers during the earliest stages of breast cancer diagnosis. The findings have been classified by age, and self or other which can be used for individualized targeted interventions to manage high anxiety levels associated with breast cancer. Our findings in this study suggest that early intervention for anxiety during the breast cancer diagnostic process may help patients cope with high levels of anxiety found in the early and mid-stages of breast cancer diagnostics. Diagnostic delays and associated uncertainty appear to amplify breast cancer related anxiety indicating that communicating early and often is important. Access to medically sound information is critical since patients are using the internet and social communities to gather information and advice. While online communities offer immediate access for information, they can serve as a source of misinformation which may exacerbate anxiety unnecessarily.

Implications for Cancer Survivors

The findings of this study suggest that improving access and awareness around breast cancer information, peer coping communities, health coaching, and forward contingency planning would benefit patients that suffer high levels of anxiety related to breast cancer diagnosis. Focusing on person centered care to include psycho-social support systems when people are coping with the possibility of breast cancer is expected to improve the anxiety associated with breast cancer investigation and diagnosis.

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Supplementary Files