

Changes in Breast Cancer Care in New York During the COVID-19 Pandemic

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Abstract: Breast cancer is the second most common malignancy among women in the United States. As such, the COVID-19 pandemic has caused medical facilities to change their methods of operation since March of 2020, including changes in diagnosis and treatment plans. New York (NY) has an unusually high incidence of breast cancer. This study analyzed the effects of the COVID-19 pandemic on breast cancer care (BCC) in NY. Women in NY that were diagnosed with or in remission for breast cancer were asked to take an online, anonymous survey regarding their BCC experience. For patients in treatment, 26% of women wished they had greater emotional support or had a family member included in their appointments. 39% of women do not feel they are receiving as good of care as before, while 31% feel they are receiving the same level of care. Additionally, 41% of women feel they received the same level of care over telemedicine. Our data show a negative correlation between the quality of care received during the pandemic and the wish for more emotional support and inclusion of supportive members in the care process (nonsignificant). There was less of a negative correlation between the quality of telemedicine care received during the pandemic and the wish for more emotional support and inclusion of supportive members in the care process (nonsignificant). This indicates that most women lacking emotional support reported worse BCC experiences, and telemedicine use was not as troublesome to patients as the lack of emotional support. Most women in treatment and in remission reported negative feelings like fear when asked about their BCC experiences. Our data show the importance of emotional support for breast cancer patients and those in remission during the COVID-19 pandemic. Our work could also provide clinicians with the knowledge necessary on how breast cancer care should be handled in an evolving pandemic such as COVID-19.

Keywords: Breast Cancer, COVID-19, Breast Cancer Care, Breast Cancer Treatment, Breast Cancer Remission, Survey Analysis, Word-Emotion Association Lexicon, Pandemic Cancer Care

1. Introduction

The COVID-19 pandemic has caused medical facilities to change their manner of operations since March of 2020. With the instruction that people stay home, there were many changes to diagnostics and treatment. These changes have affected fields of medicine such as oncology diagnosis and treatment of breast cancer [1]. COVID-19 has caused a shift in time and resources for medical facilities, including delays in diagnostics and treatment for breast cancer. Many research labs have been shut down or have shifted their focus to COVID-19, and many clinical trials have been paused, delaying valuable cancer research [2]. In terms of diagnosis, one study in the U.K. found that delays in breast cancer

diagnosis will cause many avoidable deaths due to COVID-19 [3]. Already in the U.S., there has been a decrease in cancer diagnosis since the start of the pandemic, and there is projected excess death for the next ten years from cancers such as breast cancer [2]. Women may not be getting screened for breast cancer, which may be due to delays/pauses put on this screening to minimize the spread of COVID-19 (as it was classified as non-emergent), but many women may not be getting screened due to fear as well [4]. This may result in undiagnosed cases of breast cancer, as seen in a U.K. study [1]. In terms of breast cancer treatment, there have been delays in treatment and surgeries that were

classified as “elective”. This includes no breast reconstruction following a mastectomy or lumpectomy, causing women to have to wait. One article accounts the story of a woman waiting until she could be assured that she would get breast reconstruction before she scheduled her mastectomy and being put on hormone therapy while she waited. There have also been delays in many other treatment therapies and routine visits. Chemotherapy has been adjusted to have longer periods between treatments compared to often weekly treatments before the pandemic [4]. Radiation therapy has been delayed, which may increase the risk for cancer recurrence [5]. Along with changes in BCC, there have been changes in patient and survivor perspectives of the management of breast cancer care during the pandemic. Many patients feared changes in their treatment plans and feared their cancer progression would worsen [6]. Many women also expressed feelings of sadness, fear, and anger [7]. Diagnosis, treatment, and patient perspectives of breast cancer have all gone through many changes due to the COVID-19 pandemic.

Even before the pandemic, NY has had higher breast cancer incidence rates than the rest of the country [8]. Although we have some knowledge about how COVID-19 has affected other parts of the country and world, it would be interesting to see how COVID-19 has affected BCC in NY due to its already high incidence rate. It would also be helpful to understand the opinions and thoughts on BCC and COVID-19 from current breast cancer patients or breast cancer survivors.

In this study, we surveyed 99 breast cancer patients and 151 breast cancer survivors (in remission) to observe trends related to BCC changes and gain insight into current perspectives of how the medical industry is handling breast cancer during COVID-19. Emotion was analyzed using a word-emotion association lexicon. We hypothesize that patients and those in remission will report more negative emotions and experiences concerning the pandemic. Understanding this information and these trends would allow us better to fit this new culture of COVID-19 into cancer care.

2. Materials and Methods

2.1. Online Survey Components

Two online, anonymous surveys were created using Google Forms. One survey was developed for each of the two following groups: (a) those currently diagnosed with breast cancer and undergoing treatment, and (b) those currently in remission for breast cancer, or those termed “survivors”. Survey questions consisted of general background information and demographics, questions regarding changes in diagnosis and treatment, changes in remission care, and changes in BCC in general.

Participation in the surveys required that the respondents be a female of at least 18 years of age, living in New York during the COVID-19 pandemic, and they fit into either

group (a) or (b).

2.2. Outreach

Breast cancer patients and those in remission were invited to participate in the anonymous online surveys via flyers advertised in local stores around Long Island, NY. Our team also attended breast cancer awareness events in Long Island, NY, to spread the word about our study.

We contacted breast cancer support groups and organizations on Facebook, Instagram, and Twitter via direct messaging to reach a broader audience. We asked these groups to spread the word about our surveys to their followers. Using the ad platforms available through Facebook and Instagram, our team created advertisements that would reach target audiences in NY. Our team also managed social media accounts for the study on Facebook (Molloy Breast Cancer Study), Instagram (@molloybreastcancerstudy), and Twitter (@Breast_COVID19).

2.3. Data Collection and Analysis

Survey answers were collected, and questions were categorized by question type (multiple choice or open-ended). Survey answers were put into a spreadsheet for analysis. Survey answers were analyzed using descriptive and Spearman's correlation analysis.

2.4. Word-Emotion Association Lexicon

For open-ended questions, a word-emotion association lexicon was used to analyze the emotions associated with BCC in written responses [7]. Words that were commonly used in responses (appeared at least two times) were analyzed in the word-emotion association lexicon, and significant results (“1”s) for each emotional category for each question were added with respect to the word frequency. The presence of each emotional category for a question was expressed as a percentile. Word frequency was calculated using a word counter (<https://wordcounter.net/>).

3. Results

A total of 99 women responded to the survey for women currently diagnosed with breast cancer (a), and 151 women responded to the survey for those in remission (“survivors”, (b)). All respondents were females of at least 18 years of age, and all respondents resided in New York. For those currently undergoing treatment (group (a)), most respondents classified their race as white (91.0%), with the next most common race identified as Hispanic or Latino (4.04%). For those in remission (“survivors”, group (b)), most respondents classified their race as white (93.4%), with the next most common race identified as Hispanic or Latino (4.0%) (Tables 1 and 2).

For patients in treatment (a), 26% of women wished they had greater emotional support and wished they had a family member included in their appointments. 39% of women do

not feel they are receiving as good of care as before, while 31% feel they are receiving the same level of care.

Additionally, 41% of women feel they are receiving the same level of care over telemedicine (Figure 1).

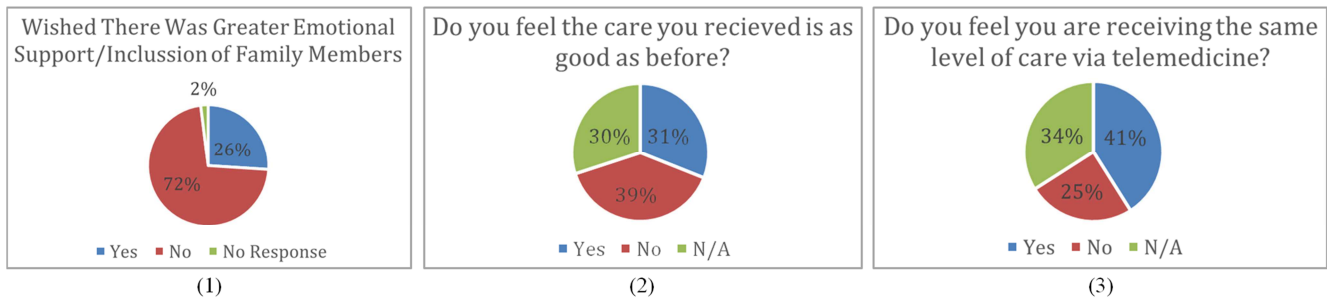


Figure 1. 26% of women in treatment wished there was greater emotional support available and wanted the inclusion of family members. 39% of respondents feel that their care is as good as before the pandemic. 41% of respondents feel they are receiving the same level of care via telemedicine.

While not statistically significant, our data show a negative correlation ($r = -.206$) between the quality of care received during the pandemic and the wish that there had been more emotional support and inclusion of family/supportive members in the care process (Table 3).

Again, while not statistically significant, there was less of a negative correlation ($r = -.090$) between the quality of telemedicine care received during the pandemic and the wish that there had been more emotional support and inclusion of family/supportive members in the care process (Table 3).

Using the word-emotion association lexicon, open-ended responses were evaluated for both groups (a) and (b). For those in treatment (a), when women were asked how they felt when the lockdown started concerning their cancer care, most women reported negative emotions (23.94%), such as fear (35.21%), sadness (11.27%), and anticipation (23.94%). When women were asked how they felt if they experienced delayed or postponed treatment, most women reported negative emotions (28.33%), such as fear (25.00%), anticipation (15.00%), and anger (13.33%). For those in remission (b), when women were asked how they felt when the lockdown started concerning their current state of remission, most women reported negative emotions (24.22%), such as fear (27.95%), anticipation (19.88%), and sadness (11.27%) (Figures 2-4).

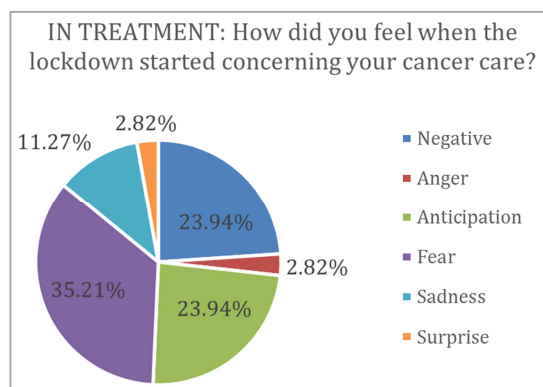


Figure 2. Most women in treatment reported negative emotions such as fear, anticipation, and sadness. Select words of high prevalence from patient responses were analyzed using the lexicon. Emotion count was calculated by adding all the "I"s (indicating a significantly associated emotion) for all words for each emotion for each question, with respect to frequency.

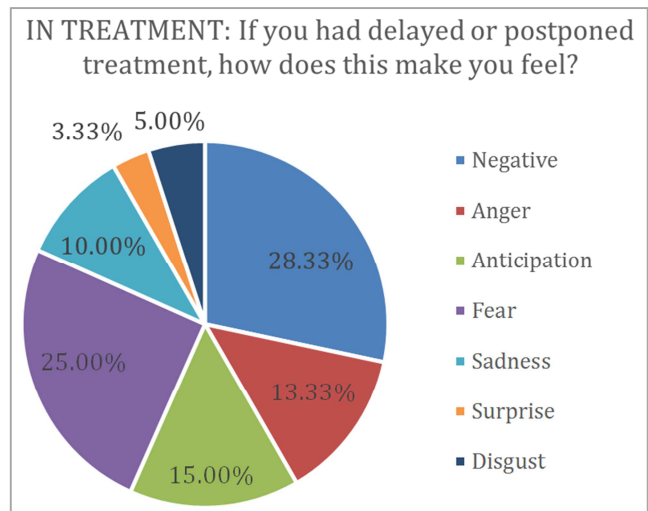


Figure 3. Most women in treatment reported negative emotions such as fear, anticipation, and anger. Select words of high prevalence from patient responses were analyzed using the lexicon. Emotion count was calculated by adding all the "I"s (indicating a significantly associated emotion) for all words for each emotion for each question, with respect to frequency.

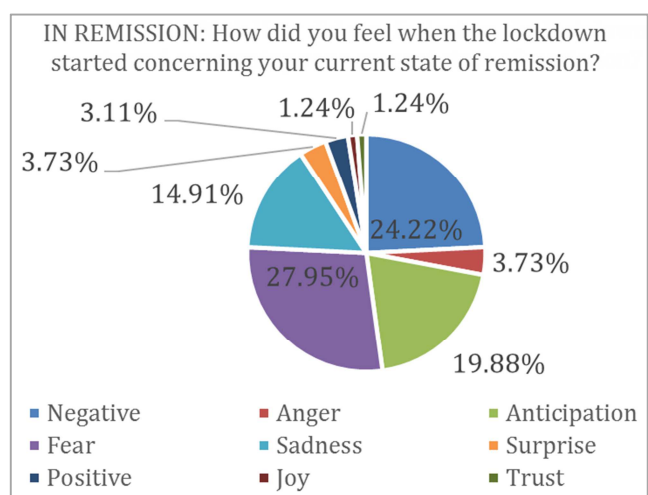


Figure 4. Most women in remission reported negative emotions such as fear, anticipation, and sadness. Select words of high prevalence from patient responses were analyzed using the lexicon. Emotion count was calculated by adding all the "I"s (indicating a significantly associated emotion) for all words for each emotion for each question, with respect to frequency.

In Treatment Group (a) Demographics

Table 1. Most respondents in treatment identified as white. Women were asked to identify their race before beginning the survey.

Race	Percent (%) of Women in Treatment
White	91.0
Hispanic or Latino	4.04
Black or African American	1.01
Asian	1.01
Other	1.01
Choose not to Answer	2.02

In Remission Group (“Survivors”) (b) Demographics

Table 2. Most respondents in remission identified as white. Women were asked to identify their race before beginning the survey.

Race	Percent (%) of Women in Remission
White	93.4
Hispanic or Latino	4.00
Black or African American	1.30
Other	0.66
Choose not to Answer	2.02

Table 3. Overall negative correlation (nonsignificant) for patients in treatment. Negative correlations were noted for the quality of care received (in general and over telemedicine) and the inclusion of family and supportive members in the care process.

Correlations			Care as good as before	Care good with Telemedicine	Emotional Support / Mental Health
Spearman's Rho	Care as good as before	Correlation Coeff	1	0.218	-0.206
		Sig (2-sided)		0.155	0.111
		N	61	44	61
	Care good with Telemedicine	Correlation Coeff	0.218	71	-0.9
		Sig (2-sided)	0.155	-0.09	0.456
		N	44	71	71
	Emotional Support/Mental Health	Correlation Coeff	-0.206	-0.09	1
		Sig (2-sided)	0.111	0.456	
		N	61	71	107

4. Discussion

This study surveyed women in NY diagnosed with breast cancer or in remission for breast cancer regarding their BCC experience during the COVID-19 pandemic. Ninety-nine women diagnosed with breast cancer and 151 women in remission responded to our surveys, and data were collected and analyzed accordingly.

While not statistically significant, the data show a negative correlation between the quality of care received during the pandemic and the wish that there had been more emotional support and inclusion of family/supportive members in the care process. In other words, those who were unhappy with the care cited a lack of emotional support, whether by mental health support services or inclusion of family/loved ones in the care process. Many studies show that including a family/supportive member in the care process is important to the patient and their care [9, 10]. Therefore, it is important not to underestimate the importance of family/supportive members as the pandemic continues and evolves. In one study that dates before the COVID-19 pandemic (February 2019), patients stressed the importance of having their family/supportive members included in all care process stages [11]. These same values and principles still apply, even in the changing nature of cancer care due to the COVID-19 pandemic, as seen by the results of our study. In fact, one study found that the inclusion of family/supportive members in the care process was critical to the improved care of each patient [12]. In another study, patients report that it was challenging not to be able to have their support person during their appointments and treatments. Patients reported feelings like being overwhelmed and not being as proficient

at interpreting the medical information without their support person [13]. Providers should assess their care process concerning the pandemic and change their care procedures as the pandemic changes, considering the patient's needs.

While not statistically significant, there was less of a negative correlation between the quality of telemedicine care received during the pandemic and the wish that there had been more emotional support and inclusion of family/supportive members in the care process. This indicates that the fact that telemedicine was used was not as important as the fact that, for some, the lack of emotional support, whether by mental health support services or inclusion of family/loved ones in the care process, was difficult. To support this, generally, most people who thought the level of care was good thought that telemedicine was as good. Telemedicine seems to be a new way that oncologists could interact with their patients, especially in the face of an ever-changing pandemic like COVID-19. Telemedicine seems to meet most of the demands of breast cancer patients, but not all patients, especially newly diagnosed patients. Telemedicine should therefore be used strategically with an emphasis on individual-based care. The emotional toll of telemedicine cannot be discounted, as the lack of in-person care could foster distrust in the provider-patient relationship [14]. On the other hand, one study notes that telehealth greatly benefits a patient's care process by allowing family/supportive members to be included in the care process [15]. Therefore, healthcare providers using telemedicine for care should make attempts to include supportive members in the care process [13]. These studies reflect the results of our study regarding the use of telemedicine. More studies are needed to assess the emotional toll of women undergoing telemedicine care for breast cancer.

Although not statistically significant, our data represent general trends that are still useful. Our data show the importance of supportive members in the care process and how the quality of BCC experiences correlates with the presence of a supportive member.

We pulled out the most common words in each question response set using the word-emotion association lexicon. We then put these words into the lexicon and calculated the presence of each emotional category for each question, accounting for the frequency. For both groups (a) and (b), the most prevalent words were nervous and anxious when women were asked about how they felt about the pandemic with their current state of breast cancer or remission. These responses resulted in a large percentage of negative emotions such as fear, anger, sadness, and anticipation. This indicates that many women felt poorly about the anticipated pandemic with their current state of breast cancer. In group (a), women mostly reported fear, anticipation, and anger when their appointments got delayed or postponed. This indicates a general dissatisfaction with cancer care during the pandemic. Our results align with other studies, such that Gebbia et al. also reported dominant emotions such as fear, anger, and sadness [7]. Other studies note that women experienced worry and concern during the pandemic [22-23, 25]. Women also reported emotional distress concerning changes to their BCC experiences [24]. This shows that our results of overall negative emotions compare to other studies. More studies are needed to analyze the patient-reported responses to the experiences of cancer care during the COVID-19 pandemic. It is important to note that our analysis only represents a small proportion of responses, as other women reported responses such as that they felt fine concerning their current breast cancer state during the pandemic, which could not be analyzed using the lexicon, while others reported responses that were less common (a frequency of 1) and were therefore not included for analysis.

Some study limitations include a lack of participation that requires revision of outreach strategies. This resulted in a small study population. Additionally, this study lacked racial diversity since most respondents identified themselves as white. Again, outreach strategies must be revised to encourage the participation of more diverse racial groups. Moreover, our study was a retrospective observational study that only captured a snapshot of the pandemic from February 2021 to September 2021. A follow-up with these patients is needed for a more up-to-date analysis. Importantly, the word-emotion association lexicon was used only on the most common words reported. Other women reported fewer common words or words that could not be analyzed using the word-emotion association lexicon and therefore were not included in the analysis.

The pandemic has greatly affected BCC and understanding how is critical to improving BCC during the pandemic. Our goal must be centered around minimizing disparities surrounding breast cancer treatment and remission care, especially during a pandemic [16]. Therefore, BCC must turn toward an individual-based care system to ensure that breast

cancer care is properly managed in future pandemics. Our results show that BCC experiences during the pandemic were more well-tolerated if the patient could have a supportive member in their appointments. Patients lacking proper support during the pandemic may experience psychological stress [17]. For example, women with breast cancer are likely to experience psychological symptoms (anxiety, depression, distress) due to the pandemic and changes to their care [18]. Like our study, other studies highlight the importance of patient support for breast cancer patients to improve BCC experiences [19]. Another study shows how patients had a hard time going through their treatments alone, like the results of our study [20]. In fact, patients who lived alone (and therefore lacked a present support system) worsened in their breast cancer state and experienced psychological disorders [21]. This reflects the importance of a supportive member in the BCC process, as indicated in our study. Our study highlights the importance of patient support in BCC during the pandemic since our data show a more tolerated BCC experience with the inclusion of a support person. Continuing support for breast cancer patients during the pandemic is critical, and our results could be used to help medical facilities structure their care more effectively during the pandemic. Our work could also provide clinicians with the knowledge necessary on how BCC should be handled in an evolving pandemic such as COVID-19. It would be beneficial if more research is conducted to understand the emotional toll on women in the in treatment and remission groups, as this data evolves with the pandemic.

5. Conclusion

In conclusion, our study surveyed breast cancer patients and those in remission regarding their BCC experience during the COVID-19 pandemic. We found that women had better BCC experiences when support and inclusion of family members was permitted. Medical facilities should continue to provide emotional support to patients, and more research should be focused on the role of supportive members in the care process. The same was found to be true with telemedicine use. Telemedicine use should be used strategically, as it may not be suitable for all patients. Additional research should assess how telemedicine use continues to change as the pandemic changes. Most patients felt negative feelings, such as fear, anger, sadness, and anticipation. This information could be used to further analyze the emotional toll on breast cancer patients during the COVID-19 pandemic. Additional work is needed to assess how patient perspectives have changed in this evolving pandemic. This study could be used to help medical facilities restructure their care during the evolving pandemic.

Abbreviations

Breast cancer care (BCC), Coronavirus Disease 2019 (COVID-19), New York (NY).

Compliance with Ethical Standards

IRB Approval This project has been approved by the Molloy College IRB, project number 1709758-1.

Conflict of Interest

The authors declare no conflict of interest.

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