



Breast Cancer Survey – Initial Impact of the COVID-19 Pandemic

As breast cancer survivors, some of whom are undergoing treatment, we all live each day with uncertainty. That uncertainty is now exacerbated by a pandemic. And that pandemic creates very real issues for all of us. Are there barriers to treatment? Should I risk going to the hospital? Doctor’s office? And many more. At NBCC we are trying to get a handle on what the issues are and then push for policies to address them. Our first step from March 24-29, 2020, was to distribute a brief, eleven question, electronic survey to our members and their respective networks about the impact of the COVID-19 pandemic on breast cancer patients, survivors, caregivers, and others. The survey included a mix of close-ended questions, partially open-ended multiple-choice response options, Likert-scaled, and open-ended response questions. The survey was distributed three times via email over five days and also promoted across social media channels, including Facebook and Twitter. We are slightly revising the questions and will keep the survey open on our website.

The primary goals of the survey were to:

- Gain a better understanding of the extent to which breast cancer survivors, both in and out of treatment, or their caregivers were experiencing challenges with access to health care as a result of the global COVID-19 pandemic.
- Characterize the nature of challenges and related issues they are experiencing.
- Identify areas around which NBCC’s public policy activities should focus to help alleviate current challenges and issues breast cancer survivors are experiencing.

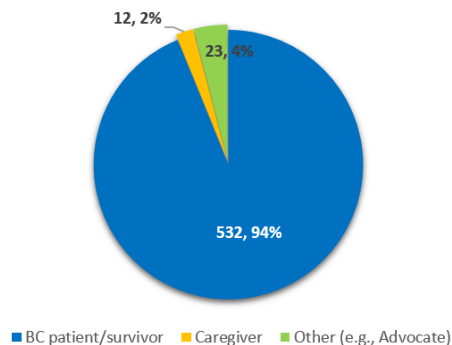
Results

A total of 568 individuals completed this convenience sample survey. Below we provide a high-level summary of responses from the survey.

Relationship of Survey Respondent to Breast Cancer

The survey began with a question to assess the breast cancer status/relationship to breast cancer of the respondent. Among 564 respondents, 94.3 percent (n=532) described themselves as “Breast Cancer Patients/Survivors.” Of these individuals, at least 5 percent (n=27) indicated they were patients living with metastatic breast cancer. Twelve individuals (2.1%) reported they were “Caregivers” for a breast cancer patient, and 23 percent (n=23) described themselves as “Other.” Among “Other” respondents, most described themselves as advocates, health care professionals, or researchers.

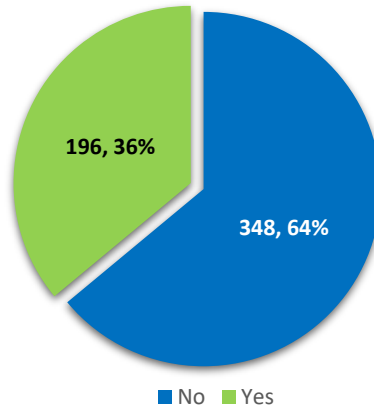
Figure 1: Respondent Category



Breast Cancer Patient/Survivor Treatment Status

Survey respondents were asked if they were presently in active treatment. Sixty-four percent (n=348) of respondents indicated “No,” while 36 percent (n=196) answered “Yes.”

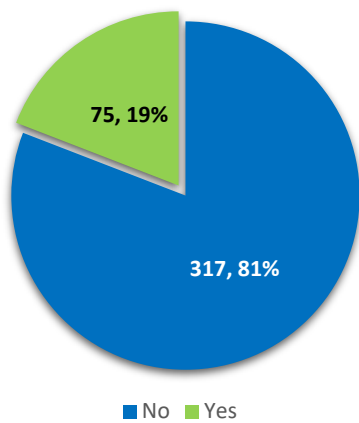
Figure 2: Treatment Status



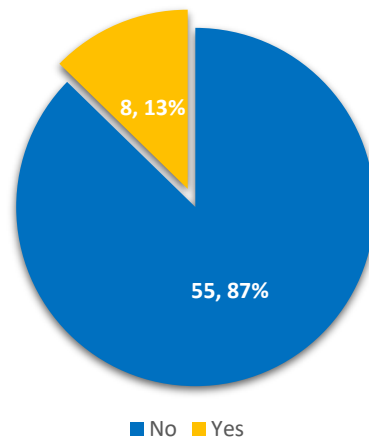
Challenges Accessing Care Related to COVID-19 Among Breast Cancer Patients/Survivors

Survey respondents were asked if they have experienced challenges accessing breast cancer treatment at their medical center, outpatient center, or doctor’s office related to COVID-19. A total of 392 people responded “Yes” or “No,” while 172 respondents indicated that this was not applicable to them. Among the Breast Cancer Patients/Survivors who responded, 19 percent (n=75) reported they had experienced challenges, while 81 percent (n=317) said they had not. (Figure 3).

Figure 3: Experienced Challenges Accessing Breast Cancer Care/Services Related to COVID-19?



Among Breast Cancer Patients/Survivors



Among Caregivers

Noted Challenges in Accessing Care

Survey respondents were asked to describe the nature of the challenges they experienced. A total of 82 individuals responded to this question, including both patients/survivors and caregivers. Free text responses were classified according to 12 different themes that emerged from a content analysis. (Figure 4). The largest proportion of responses related to canceled or postponed follow-up assessments such as, blood tests or imaging. A smaller percentage of respondents noted postponement of treatments and infusions. Respondents noted that visits with their health care provider were “virtual,” which was concerning to some. Yet, a number of individuals expressed concerns about in-person doctor appointments and treatments as a result of being immunocompromised and concern about possible exposure to the coronavirus.

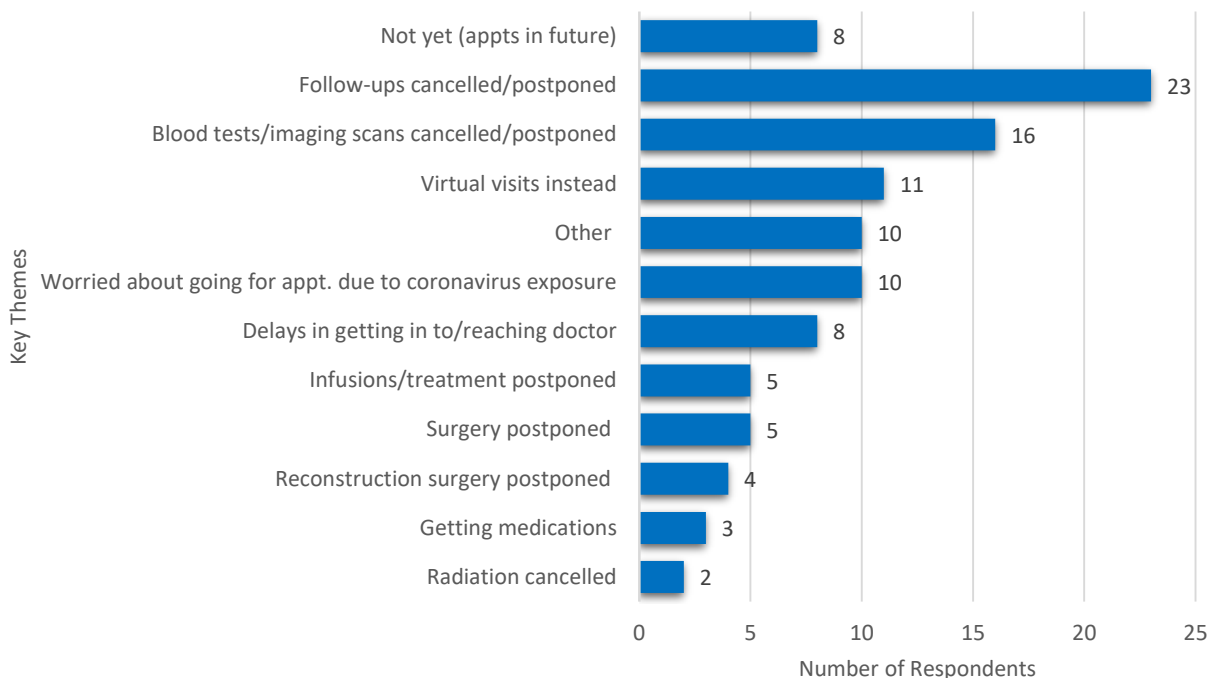
Example Responses

“I was asked to skip an infusion to keep the infusion center less crowded and reserved for the sickest patients...”

“All medical appointments/ treatments in Puerto Rico for U.S. Virgin Islanders with breast cancer have been canceled.”

“My radiation, physical therapy ... and reconstruction appointments were all canceled...”

Figure 4: Nature of Challenges



Access to COVID-19 Testing

Respondents were asked if they had been denied access to COVID-19 testing if they had reported to their health care provider that they were experiencing symptoms. The vast majority (96%, n=465) had not reached out to their provider for this reason. However, four percent (n=17) reported being denied access to COVID-19 testing.

Access to Prescription Drugs

Respondents were asked if they were experiencing difficulties filling prescriptions as a result of COVID-19. The vast majority of respondents (91%, n=428) indicated they were not, while approximately nine percent (n=41) reported that they were.

Contacted By Health Care Provider and Helpfulness of Information Provided About COVID-19

NBCC asked if patients had been contacted by their health care professionals with medical advice or information on how they could protect themselves against COVID-19 or access care should they have symptoms. Approximately 39 percent (n=200) indicated that they had been contacted, while approximately 61 percent (n=318) indicated that their healthcare provider had not contacted them.

The 39 percent (n=200) who were contacted also were asked to rate how helpful the information or advice was that they received. Notably, 58 percent (n=133) of respondents reported that the information they received was “Very” or “Extremely Helpful.” A total of 30 percent responded information was “Somewhat Helpful, while approximately 13 percent (n=29) indicated that it was “Not So Helpful” or “Not at All Helpful.”

Insurance/Payment Concerns

Participants were asked if they had insurance or payment concerns related to their care and treatment if they were to be diagnosed with COVID 19. A total of 445 respondents (83%) indicated that they did not, while 89 respondents (17%) reported that they did have concerns. Among the latter, the vast majority of responses centered on high deductibles and out-of-pocket expenses for treatment. Some were worried about the possibility of losing insurance because of a possible loss of their job should they become sick.

Other Concerns/Challenges

A final open-ended question asked about other challenges, as a result of the pandemic that they have experienced as a breast cancer patient or caregiver, which they would like to share with NBCC. A total of 152 survey respondents answered. A content analysis identified 13 key themes, which are shown in Figure 5 below. The largest proportion of responses related to fear of, or being, immunocompromised and their high risk of exposure and more general anxiety and emotional stress. Other concerns related to the unknowns of their ongoing treatment and care, as well as access to needed care.

Example Responses

“High deductible insurance plan and self-employed.”

“As part of a high deductible plan ..., I do have concerns with being able to pay the medical bills.”

“Financial concerns if me or family member is diagnosed and require hospitalization and loss of work.”

“Not being able to afford treatment.”

Example Responses

“Anxiety; worried about not getting my cancer treatments or getting sick because they give me my treatments at the hospital.”

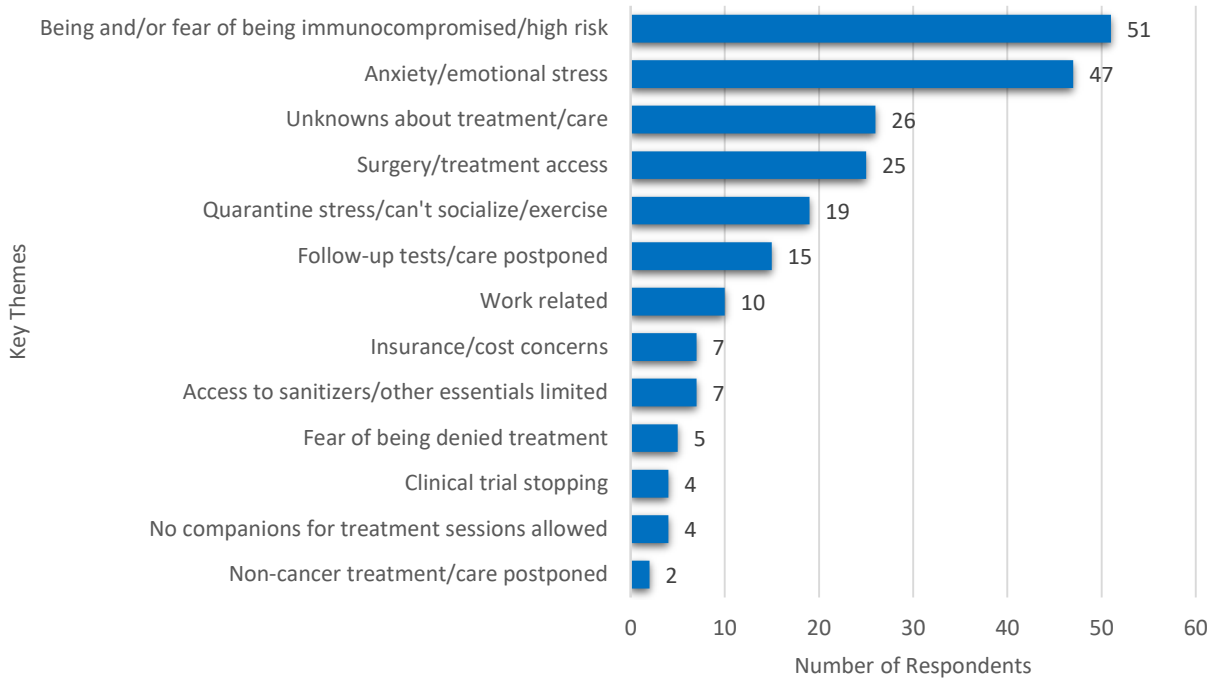
“Constant fear that you are going through cancer treatments and just needing a little bit more support.”

“Clinical trial being stopped.”

“Do I continue going to the hospital for my treatments, or is it safer to skip treatment and stay home for a few weeks?”

“Do I go to my cancer center or to another major medical center?”

Figure 5: Other Challenges/Concerns Resulting from the Pandemic



Geographic Distribution of Respondents

A total of 318 respondents (56%) identified the state in which they live. As shown in the figure below, a total of 43 states were represented, with 37.8 percent (n=121) of responses (among those reporting their state) coming from Delaware, California, and New York.

Figure 6: Geographic Representation of Survey Respondents



Conclusion

In line with the goals of this survey, NBCC observed that there are a number of issues and concerns that breast cancer survivors are experiencing as a result of the current global COVID-19 pandemic. Less than one month following the onset of the COVID-19 pandemic in the U.S., we found that 19 percent of survey respondents indicated that they had experienced challenges accessing care during COVID-19, most related to cancellations and/or postponed follow-up visits, blood tests, imaging, treatments/infusions, and surgeries, among others. Over 17 percent of respondents have concerns related to insurance and payment issues should they become infected. Nearly 10 percent of respondents are already experiencing difficulties filling prescriptions, and 4 percent of respondents have reported being denied access to COVID-19 testing after reporting symptoms.

NBCC recognizes that the current environment in the United States is evolving rapidly and that the challenges and disruptions in regular care for breast cancer patients in active treatment are only likely to increase. NBCC will continue to monitor the situation, and collect and analyze data from breast cancer survivors and their caregivers over the coming weeks. We will also continue to identify areas in which NBCC will work to ensure all patients are receiving the best available care according to current and somewhat fluid guidelines.