



Patient Perceptions of Changes in Breast Cancer Care and Well-Being During COVID-19: A Mixed Methods Study

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ABSTRACT

Background. Widespread healthcare restructuring due to the COVID-19 pandemic led to modifications in the timing and delivery of care for breast cancer patients. Our study explores patient concerns relating to COVID-19, breast cancer, and changes to breast cancer care.

Patients and Methods. Breast cancer patients who presented for surgical consultation at an academic, multidisciplinary clinic completed the electronically distributed validated COVID-19 Impact and Healthcare Related Quality of Life questionnaire between August 2020 and February 2021. This questionnaire uses Likert score responses to assess COVID-specific concerns within domains, including distress and financial hardship. Scale scores were determined by averaging items within each domain, and scores > 2 indicated greater disruption. Semistructured interviews were conducted with patients who indicated interest in participating in the questionnaire.

Results. Of 381 patients recruited, 133 patients completed the questionnaire and 20 patients completed interviews. Sixty-three percent of survey participants reported attending a telemedicine appointment for their cancer care, and

the majority (67%) were satisfied with their experience. Half of the participants (50%) reported fear about how the COVID-19 pandemic will impact their cancer care or recovery, and 66% reported anxiety about contracting COVID-19. Twenty-two percent of participants reported decreased income due to COVID-19. Patient interviews revealed tangible changes to care and provided in-depth information on the advantages and disadvantages of telehealth.

Conclusions. Breast cancer patients report anxiety about COVID-19 infection and potential care modifications. Our study identifies impacts on patients' care and quality of life. Further investigation will inform interventions to improve psychosocial outcomes for patients and the telehealth experience.

The World Health Organization declared COVID-19 a Public Health Emergency of International Concern on 30 January 2020, which led to widespread healthcare restructuring.¹ The changes in the healthcare system led to delays in the initiation of treatment for many breast cancer patients, as well as modifications to both systemic and surgical treatment.^{2–4} Existing studies show that changes in cancer care due to the COVID-19 pandemic are associated with delays in treatment, increased patient anxiety and concern about both cancer prognosis and contracting COVID-19, and patient hesitancy with respect to communicating their health concerns.^{4–7} These consequences may lead to emotional distress, loneliness, and social isolation, all of which have been shown to contribute to negative clinical outcomes for cancer patients.^{8–10} With this study, we aim to build upon current literature, pairing

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questionnaires with semistructured interviews to take a deeper dive into concerns specifically within the breast cancer population. Using this mixed methods approach, we aim to (1) describe patient concerns about COVID-19 and their breast cancer care and (2) qualitatively assess patient perceptions of changes in their care.

PATIENTS AND METHODS

Study Design

Breast cancer patients who presented for surgical consultation at an academic multidisciplinary clinic in Colorado were recruited to participate in our study. The survey was administered from August 2020 to February 2021. Eligible patients included patients receiving some form of breast cancer care during this period and included those patients who received a breast cancer diagnosis prior to the start of the pandemic. Patients with all stages of breast cancer were eligible for inclusion.

Patients completed the electronically distributed validated COVID-19 Impact and Healthcare-Related Quality of Life (COVID-19 IHRQL) questionnaire.¹¹ The questionnaire was delivered through email and completed in RedCap. Patients who completed the questionnaire and indicated interest in further study participation were contacted by telephone for a semistructured interview. Clinicodemographic variables including age, clinical anatomic stage, race, and ethnicity were collected through review of the electronic medical record. Postcard consent was obtained for the questionnaire and verbal consent was obtained for phone interviews. The study was approved by the University of Colorado's institutional review board (COMIRB #20-1434).

COVID-19 Impact and Healthcare Related Quality of Life Questionnaire

The COVID-19 IHRQL questionnaire assesses COVID-19-specific concerns within the domains of distress, healthcare and daily life disruptions, financial hardship, perceived benefits, functional social support, and perceived stress management, using Likert score responses ranging from 0 (strongly disagree) to 4 (strongly agree). Scale scores were determined by averaging individual items within each domain, with a score greater than 2 indicating greater disruption in that domain, a process outlined in the scoring rubric for the questionnaire.¹¹

Semistructured Interviews

Semistructured interview questions were developed using an iterative judgmental review process by a panel of experts in breast cancer care.¹² Item- and scale-content validity analyses determined the questions to be relevant and clear to our study aims.¹³ Supplementary Table 1 includes the scoring sheet used to guide experts. Interview participants completed 15-min semistructured telephone interviews with open-ended questions focused on tangible changes to their breast cancer care, experience with any telehealth visits, and mental health and social support changes that may have occurred due to the COVID-19 pandemic. All interviews were conducted by a single interviewer (A.L.). Supplementary Table 2 contains the complete interview guide.

All interviews were audio-recorded and transcribed verbatim by the interviewer (A.L.). Verbal consent was obtained for audio recording. The transcribed documents were reviewed and all patient identifiers were redacted. A subset of the transcriptions was reviewed and a coding rubric was created to identify recurrent themes through patient narratives. Three researchers (S.P.M., A.L., V.H.) independently reviewed all interview transcriptions for thematic elements. Interrater reliability was determined through calculation of the Gwet agreement coefficient, which provides ranges for agreement.¹⁴

RESULTS

Patient Characteristics

The COVID-19 IHRQL questionnaire was emailed to 381 patients and completed by 133 (35%). Respondents were diagnosed between June 2019 and November 2020 and were receiving breast cancer care during the pandemic. Twenty (5%) patients participated in semistructured interviews. Table 1 summarizes the characteristics of the survey participants. The vast majority of survey participants were greater than 45 years old (87%), White (89%), and diagnosed with stage I or II invasive breast cancer (73%) or ductal carcinoma in situ (17%). Similarly, the majority of survey nonrespondents were greater than 45 years old (76%), White (87%), and diagnosed with stage I or II invasive breast cancer (75%), or ductal carcinoma in situ (15%).

COVID-19 Impact and Healthcare Related Quality of Life Questionnaire

Twenty-four percent of patients reported a comorbidity associated with an increased risk for severe COVID-19 including diabetes, hypertension, kidney disease, or

TABLE 1 Patient characteristics

Characteristic	Cohort (N = 133) n (%)
<i>Age (years)</i>	
Young (< 45)	17 (12.78%)
Middle (45–62)	61 (45.86%)
Elderly (> 62)	55 (41.35%)
<i>Race</i>	
Black	7 (5.26%)
White	119 (89.47%)
Other	5 (3.76%)
Unknown	2 (1.50%)
American Indian/Native American/Alaskan Native	0 (0%)
Asian	0 (0%)
<i>Clinical anatomic stage</i>	
0	23 (17.29%)
1	59 (44.36%)
2	39 (29.32%)
3	10 (7.52%)
4	2 (1.50%)
<i>Comorbidities such as diabetes, hypertension, kidney disease, and/or respiratory illnesses (e.g., COPD, asthma)</i>	
Yes	32 (24.1%)
No	101 (75.1%)
<i>Positive COVID-19 diagnosis</i>	
Yes	1 (0.7%)
No	132 (99.3%)

respiratory illnesses. Eighty-four percent of patients reported participating in a telehealth medical appointment during the COVID-19 pandemic, and 63% of patients reported attending a telehealth appointment specifically for their breast cancer care. The majority of patients (67%) reported that they were somewhat or very satisfied with their telemedicine experience. Five percent of patients reported that a family member or member of their household were diagnosed with COVID-19, and 45% reported that a friend, coworker, or neighbor had been diagnosed with COVID-19. Table 2 includes scale scores for each domain.

Figures 1 and 2 include survey results from selected items on the COVID-19 IHRQL questionnaire. Notably, 18% of patients reported that their cancer care was disrupted or delayed due to the COVID-19 pandemic, and 50% reported concerns about how the COVID-19 pandemic will impact their cancer care or recovery. Sixty-six percent of participants reported anxiety about infection with COVID-19. Mental health concerns during the COVID-19 pandemic were also commonly reported—47% of patients reported experiencing sadness or depression and 41% reported having negative or anxious feelings about the

future. Regarding their experience at the breast center, 86% of participants felt that healthcare providers had taken adequate measures to address COVID-19, and 71% felt that they received enough information about COVID-19 from their cancer care providers.

Semistructured Interviews

Gwet agreement coefficients for interview questions ranged from 0.6 to 1.0 for the categories, indicating good or very good agreement in interrater reliability (Supplementary Table 3).¹⁴

Tangible Changes in Care Due to the COVID-19 Pandemic

Patients reported tangible changes in their care including telehealth visits, delays in their care, location changes, and visitor limitations. Delays in care were due to cancellations of diagnostic procedures, such as biopsies, as well as delays to elective reconstruction. Patients reported having to seek care at alternative healthcare locations either because of COVID-19 outbreaks at their home institutions,

TABLE 2 COVID-19 psychosocial and practical experiences

Item	Median (IQR)
Distress subscale	2.31 (1.69–2.84)
Healthcare disruptions and concerns subscale	1.00 (0.75–1.75)
Disruption to daily activities and social interactions subscale	2.00 (1.33–2.50)
financial hardship subscale	1.00 (0.80–1.60)
Functional social support subscale	1.25 (1.00–1.75)
Perceived stress management subscale	1.40 (1.00–1.75)
Emotional distress subscale	2.30 (1.70–2.90)
Anxiety subscale	2.60 (1.80–3.00)
Depression subscale	2.00 (1.00–3.00)
Disruption composite score	1.47 (1.13–1.87)

Questionnaire assesses COVID-19 specific concerns in the above domains using Likert score responses, ranging from 0 (strongly disagree) to 4 (strongly agree). Scale scores were determined by averaging individual items within each domain, with a score > 2 indicating greater disruption in that domain

or to minimize COVID-19 exposure by receiving care at a less crowded facility:

“I preferred to get my care at the Highlands Ranch facility versus Anschutz, simply because there weren’t as many people and I felt like my risk of exposure was lower.” 62-Year-old patient with ductal carcinoma in situ (DCIS)

Visitor limitations were also a significant concern for some patients, especially during the preoperative and postoperative periods on the day of surgery. Figure 3 includes selected quotes about experiences with visitor limitations. Patients also highlighted risk-reducing measures at the facility, including social distancing in lines and in waiting rooms, mask wearing by providers and patients, and enhanced cleaning protocols. A patient described improvements in communication with providers:

“I think because all of the providers that I had during this time with my breast cancer have been incredible and they have just been so caring... I could just tell she wished that she was able to just put her hand on my shoulder and be like hey we got it, you know... I could tell with them, that they felt the same way I did.” 50-Year-old patient with DCIS

Additionally, some patients also reported no meaningful changes in their care.

Changes to Patient Well-Being

Patients frequently reported changes to their well-being during the COVID-19 crisis, including emotional, physical, and financial changes. Emotional concerns were the most prevalent and included anxiety, depression, and emotional changes due to social isolation. Two quotes describing the experience of social isolation are below:

“I have not seen anybody in person since the day that I went to the multidisciplinary clinic and met all the providers, I’ve been really isolated and that’s very difficult. Not seeing my family in person and them not be able to see me.” 54-Year-old patient with stage 2 breast cancer

“I feel like normally I would see more of my friends when I’m going through cancer, or family members, but because of the need to stay not infected with COVID-19, I haven’t been able to.” 45-Year-old patient with stage 2 breast cancer

Physical changes were also reported as exercise was reduced or modified to prevent exposure to COVID-19. Some patients reported financial concerns or experienced a loss of employment during the COVID-19 period.

Telehealth Experience

Patients reported both positive and negative aspects of their experience with telehealth. Advantages included ease of scheduling, greater convenience, and reduced potential for COVID-19 exposure. Other patients described neutral experiences with telehealth, perceiving no meaningful differences in the care or communication with their provider compared with what they would have expected during an in-person visit. Disadvantages included privacy concerns, feeling rushed, feeling impersonal, connectivity problems, and communication challenges, as well as concerns about a lack of a physical examination. The lack of a physical examination was the most commonly reported disadvantage of telehealth examinations. Telehealth visits were reported with our supportive oncology providers, nutritionists, genetic counselors, and medical oncologists, as well as other providers outside of the breast center. Some patients found certain types of visits more amenable

A COVID-19 Specific Concerns



B Healthcare Disruptions and Concerns

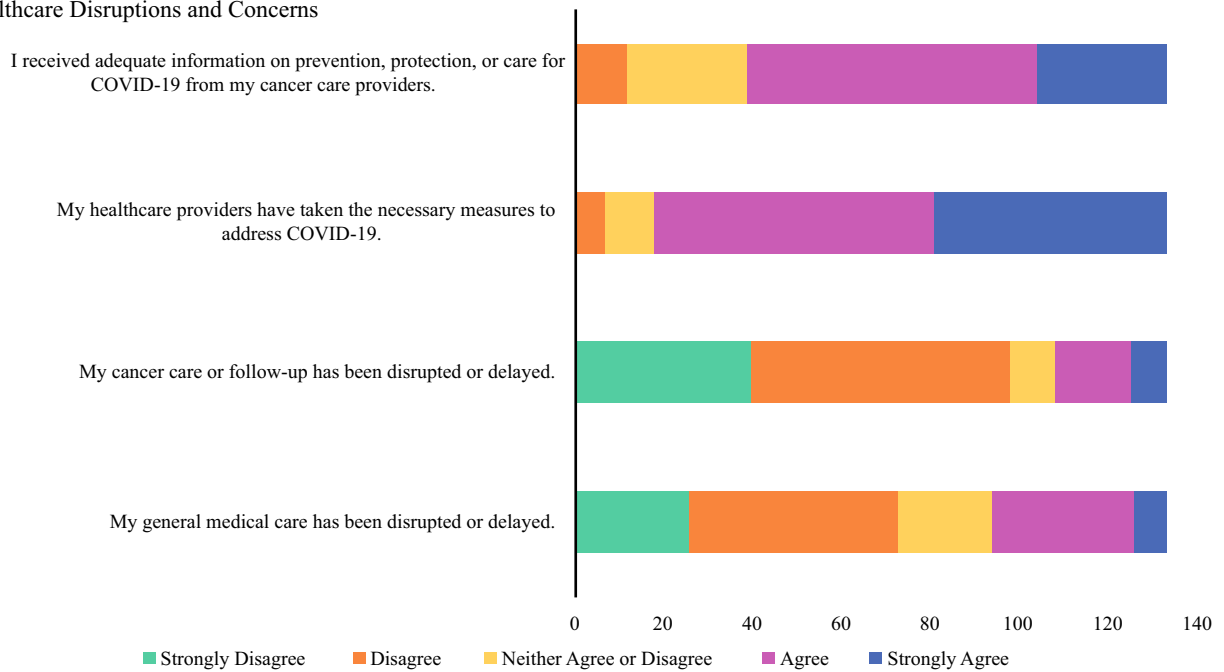
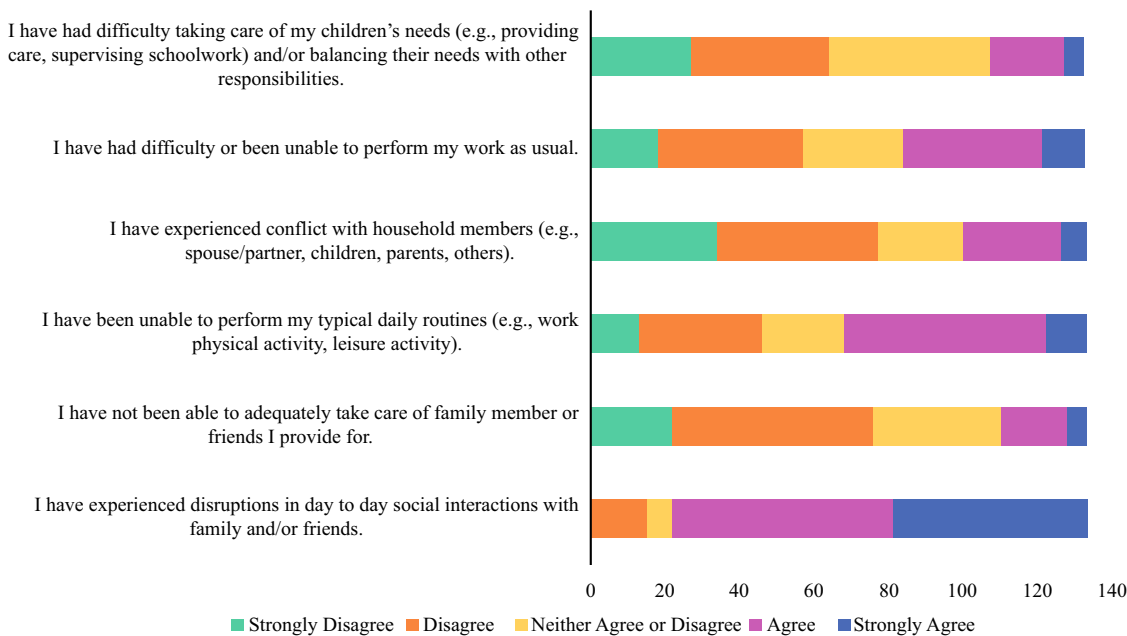


FIG. 1 COVID-19 and healthcare items from the COVID-19 IHRQL questionnaire: Patients rated their agreement to a set of statements on the COVID-19 IHRQL questionnaire using a Likert scale, ranging from strongly disagree to strongly agree

to telehealth than others, specifically visits that would not have included a physical examination if it had been done in

person. Figure 4 includes selected quotes about the telehealth experience.

A Daily Life Disruptions



B Financial Concerns

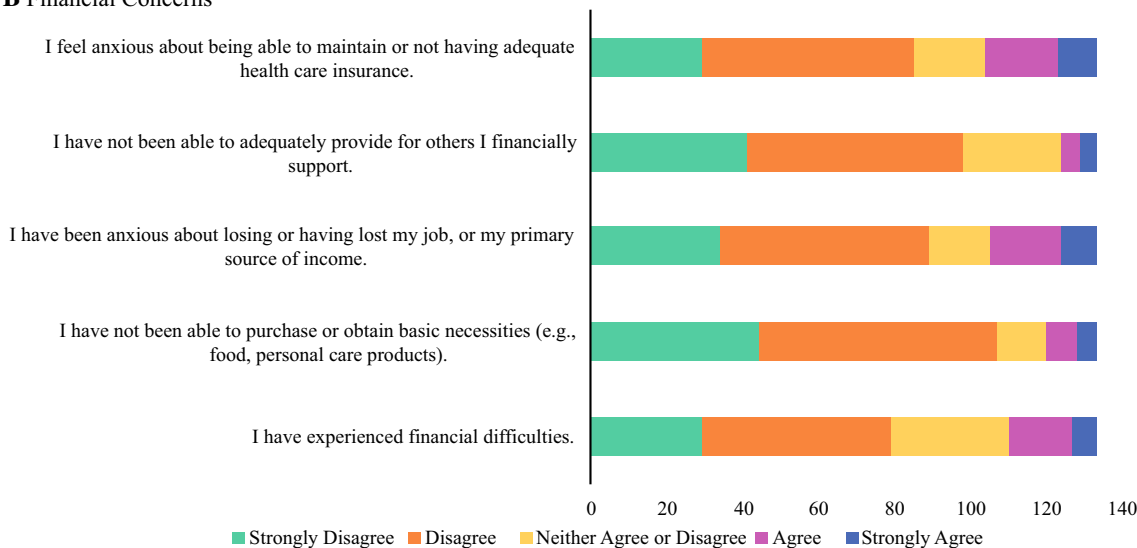


FIG. 2 Practical concerns from the COVID-19 IHRQL questionnaire: Patients rated their agreement to a set of statements on the COVID-19 IHRQL questionnaire using a Likert score response, ranging from 0 (strongly disagree) to 4 (strongly agree)

COVID-19-Specific Concerns

Patients frequently reported COVID-19-specific concerns. These concerns included their own or loved one's infection with COVID-19, as well as general uncertainty related to the pandemic. Additionally, patients discussed their own efforts to alleviate their risk of infection through activity restriction and a reduction of in-person social interaction.

DISCUSSION

Our study characterizes current patient concerns related to COVID-19 and their breast cancer care, highlighting opportunities for improving psychosocial aspects of care and the care provided through telehealth. Notably, we found that our patients are experiencing mental health concerns, such as anxiety and depression, as well as emotional changes related to social isolation. Additionally, many feared disruptions to their cancer care and recovery due to the COVID-19 pandemic, and approximately a fifth

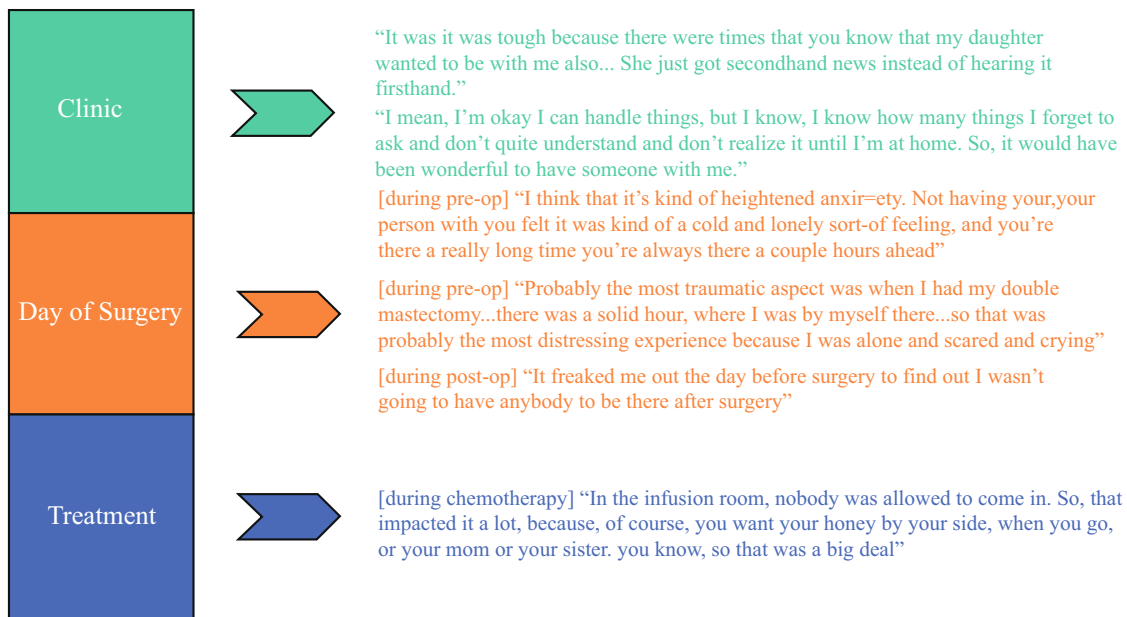


FIG. 3 Representative quotes on visitor limitations: Patients participated in semistructured interviews and their responses were transcribed verbatim. Representative quotes relating to visitor limitations at various points in care were selected

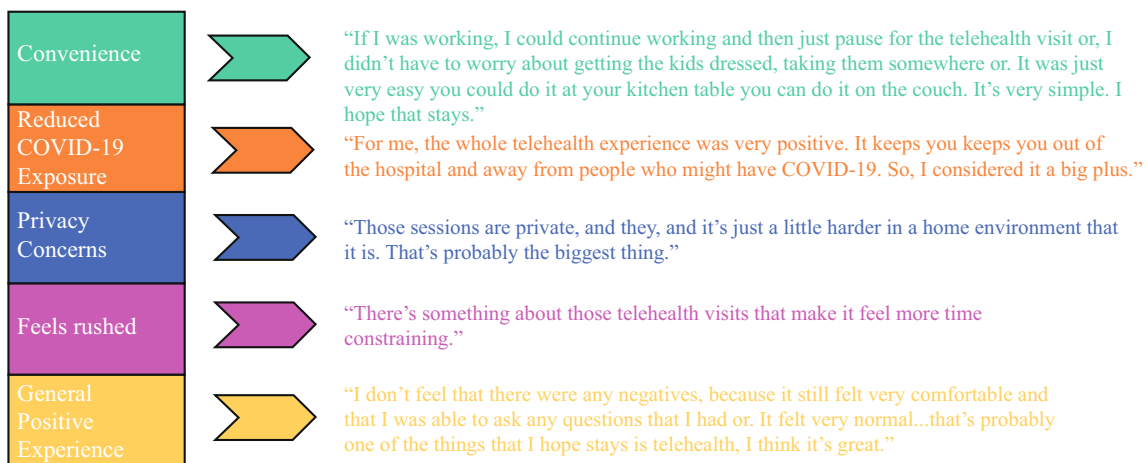


FIG. 4 Representative quotes on telehealth experience: Patients participated in semistructured interviews and their responses were transcribed verbatim. Representative quotes about aspects of the telehealth experience were selected.

of our patients reported delays or disruptions to their care. Patients appreciated some of the accessibility and risk-reduction benefits of telehealth visits, but also described some of its key limitations. Patient interviews elucidated the importance of visitors to the patient experience, especially during chemotherapy and on the day of their surgery.

Some tangible changes in care experienced by patients—including delayed diagnosis and treatment—pose a potential concern for long-term outcomes, as literature shows that delayed diagnosis and longer time to surgery is related to lower overall survival.¹⁵ Another study evaluating the effects of the pandemic on breast cancer care found that more than 40% of patients experienced delays in

treatment.¹⁶ These delays can be distressing—Chen et al. found that delayed medical care during COVID-19 in a population of gynecologic oncology patients was associated with increased anxiety levels.¹⁷ Breast cancer patients may be uniquely at risk for experiencing distress, as a recent study assessing the psychosocial effects of the pandemic on cancer patients found that breast cancer patients, specifically, reported significantly higher COVID-19-specific distress.¹⁸ Additionally, there may be an increase in patients whose diagnosis has been delayed due to COVID-19, as studies found a decrease in breast cancer screening of upwards of 85% during the peak of the pandemic.^{19,20} Delays in breast reconstruction, which were

also reported, may have a more positive outlook, as studies have found that delayed reconstruction may have better operative and aesthetic outcomes, and similar patient satisfaction and well-being outcomes.^{21,22}

Patients' loss of social interaction due to the COVID-19 pandemic may have clinical implications. Studies have shown that the level of social support in breast cancer patients is positively related to psychological resilience, and physical and health-related quality of life.^{23–25} This may even contribute to clinical outcomes, as studies have found that contact with friends and family after a breast cancer diagnosis was associated with lower risk of death, and that social isolation was related to mortality.^{26,27} Measures taken by patients to reduce their risk of being infected with COVID-19, through limiting social interaction and avoiding public spaces, may impact their social support and psychological well-being, and their ultimate clinical outcomes. Visitor limitations may impact the social support that patients feel they have at key points in their care—especially during chemotherapy and surgery—and future investigation should include ways to maximize familial involvement in care, even when they cannot be physically present.

Despite distinct challenges to breast cancer care delivery during the pandemic, the transition of some care to telehealth proved to be largely favorable from the patient perspective. During interviews, many patients were satisfied with their telehealth experience and reported interest in a continuation of telehealth opportunities at the breast cancer center after the pandemic ends. However, patients reported varying levels of comfort with the telehealth setting based on the type of visit they were seen for and whether they felt they needed a physical examination. Our results mirror those found at another institution, where the majority of patients reported telehealth saved them time, improved their access to care, and improved their overall health.²⁸ Telehealth visits may not be able to provide some things—physical examinations, for example—and socioeconomic disparities may impact participation.²⁹ While not investigated in our study, telehealth may also be less favorable to both patients and providers for patients' initial breast cancer multidisciplinary visit. However, future technology improvements and improved patient and provider comfort with the telehealth system may be able to mitigate some of the other limitations reported by our patients, including connectivity and communication problems, feeling impersonal or rushed, and privacy concerns. Ours and other research suggests that telehealth may be a lasting feature of cancer care and follow-up.

Limitations of our study include that it was conducted at a single institution. Additionally, the potential for statistical conclusions from our data was limited by a small sample size. Our study lacks the information required to compare

characteristics of eligible patients who completed the survey with those who did not complete the survey as surveys were emailed, and we cannot determine whether patients ever opened the email invitation. However, the strengths of our study are its combination of quantitative and qualitative analysis to investigate breast cancer patient concerns during the COVID-19 pandemic. Further investigation includes follow-up of clinical outcomes in patients who experienced care delays or disruptions, exploring ways to improve patient comfort when visitors cannot be present or there are concerns about social isolation, along with avenues for improving the telehealth experience by identifying specific opportunities to mitigate patient concerns about the use of telehealth and providing patient confidence when a physical examination is not possible or less desirable. Additional investigation should also include determining whether psychosocial experiences during the pandemic were correlated with demographic or disease characteristics of our patients, and whether they experienced delays in care.

CONCLUSIONS

Breast cancer care was modified due to the COVID-19 pandemic, and our patients perceived tangible changes in their care, including delays in diagnosis and treatment, a transition of some appointments to telehealth, and visitor limitations at our facility. Alongside tangible changes in care, patients experienced psychosocial changes—including anxiety, depression, and social isolation, as they attempted to reduce their exposure to COVID-19. The additional burden of the COVID-19 pandemic added to the mental distress patients already experience when faced with a cancer diagnosis. Our study provides key insights into these challenges and provides information that will inform future research into interventions to improve psychosocial support of patients undergoing breast cancer treatment and the telehealth experience.

Supplementary Information The online version contains supplementary material available at <https://doi.org/10.1245/s10434-021-11209-1>.

DISCLOSURES The authors have no disclosures.

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