



# A Qualitative Study of the Impact of the COVID-19 Pandemic on Metastatic Breast Cancer Care

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## Abstract

The COVID-19 pandemic substantially impacted the delivery of oncology care, particularly for individuals with metastatic cancers. The objective of this study was to qualitatively evaluate the impacts of COVID-19 on metastatic breast cancer (MBC) care among patients. This study consisted of 36 semi-structured qualitative interviews conducted virtually with people living with MBC, who were members of a patient support organization called Project Life. Project Life is an MBC patient-led, web-based wellness community. Responses were analyzed using Phronetic Iterative Analysis. Interviews were conducted from March 14, 2022, to May 31, 2022. Analysis from 36 individual in-depth qualitative interviews revealed the following themes during COVID-19: (1) variable preferences for telehealth (2) disruptions to care, (3) virtualization of social care. Wide variations existed in preferences surrounding telehealth, centered around ideas of convenience. Disruptions to care included delays to diagnostic care, isolation from caregivers, and interruptions associated with COVID-19 infection. These results call for adaptability in oncology care given wide-ranging preferences on telehealth and the shifting of available support services.

## Keywords

metastatic breast cancer, patient engaged research, COVID-19, qualitative study

## Introduction

On average, 16,000 recurrent and de novo metastatic breast cancer (MBC) cases are diagnosed each year.<sup>1</sup> People can live with MBC for years, with around one-third living five or more years after their initial diagnosis.<sup>2</sup> The lifelong treatment regimens commonly cause side effects including lymphedema, radiation dermatitis, neutropenia, and back pain.<sup>3</sup> Besides physical symptoms, mental, economic, and sexual health are also issues, where anxiety, depression, uncertainty, financial toxicity, and end of life coping may manifest, creating a need for social supports.<sup>4,5</sup>

Support from family and friends plays a vital role in countering the side effects of MBC care and promoting quality of life,<sup>5</sup> and so too do psychological interventions.<sup>6</sup> Social support programs also serve as a source of resilience,<sup>7</sup> through virtual and in-person formats<sup>8-10</sup> that vary in structure<sup>11</sup> from those internal to medical institutions to those driven by external patient-led and/or community-based efforts.

Throughout the COVID-19 pandemic, people living with MBC have faced exceptional vulnerability, due to the

necessity of in-person medical care, immunosuppression from treatment and reduced efficacy of the COVID-19 vaccine.<sup>12,13</sup> While research has detailed special considerations for breast cancer patients receiving treatment during COVID-19,<sup>14</sup> few studies explicitly focus on patients with MBC. In the studies that have addressed MBC care during

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the pandemic, they have been clinical in nature, leaving a dearth of research that explicitly includes the patient voice.<sup>15,16</sup> To address this gap, the objective of this study was to partner with an MBC patient organization called Project Life to qualitatively evaluate the impact of the COVID-19 pandemic on cancer care delivery for people living with MBC.<sup>17</sup>

## Methods

An academic-patient organization connection was cultivated over the span of several months via Zoom with JM from non-profit organization Guiding Researchers and Advocates to Scientific Partnerships (GRASP), which is an organization dedicated to empowering patients, clinicians, and researchers to exchange impactful ideas. Academic study team members MLR and JW were introduced to LG and DJ with Project Life, a patient-led, non-profit, web-based wellness organization for those living with MBC by JM. Project Life is a membership-based online community for people living with MBC and their loved ones that provides curated regular content and workshops on living with MBC.

Participants for in-depth semi-structured one-on-one interviews were purposively recruited from the MBC patient organization, Project Life. The sampling frame consisted of all registered members of the Project Life virtual community. Individuals could become Project Life members by registering for the wellness community on its website for free. Members who are confirmed to be living with MBC or caregivers of someone living with MBC can join the community. Recruitment materials were co-created by all study team members across Project Life and GRASP. LG distributed recruitment information to Project Life's membership list of 405 people, which detailed the overarching study topic of understanding experiences living with MBC. Potential participants were asked to complete a brief screener survey to confirm eligibility for the qualitative interviews. Eligible participants were 18 years or older, were Project Life members, were living with MBC, were able to complete a Zoom call, and were English-speaking.

The interview guide was co-created by MLR, JW, LG, DJ, and JM incorporating both academic and patient perspectives in the conduct of the study. The interview guide was developed initially by MLR and JW and was refined in biweekly meetings with LG, DJ, and JM to determine the most salient areas of inquiry. Interview questions included items relating to experiences at diagnosis with MBC, experiences of treatment for MBC, experiences of how the COVID-19 pandemic affected MBC treatment, and how participants would re-imagine MBC care based on their lived experience.

Following completion of the screener survey, MLR contacted each participant to schedule one, 1-hour interview to be conducted over Zoom, using the co-created interview guide while recording audio as permitted through informed consent. One-on-one interviews were conducted virtually and audio-recorded from March 14, 2022, to May 31,

2022. Interviews were transcribed from audio recordings using NVivo transcription and manually quality-checked for accuracy by MLR.

Guided by standards for qualitative research set by the Patient-Centered Outcomes Research Institute (PCORI),<sup>18</sup> data were processed in MAXQDA using Phronetic Iterative Data Analysis (PIA).<sup>19</sup> PIA is a systematic multi-step form of qualitative analysis that utilizes a constant comparative method, whereby data are analyzed in multiple phases for both inductive and deductive codes.<sup>19</sup> Deductive codes were created a priori based on a synthesis of existing quantitative literature and with input from patient collaborators LG, DJ, and JM. For analysis, initial, blind coding was performed by JW, further non-blind analysis was completed by MLR, and added refinement of themes was conducted by LG, JM, DJ, SNCE between March 14, 2022 and August 1, 2022. Throughout the conduct of the research, member checks from patient organizations Project Life and GRASP (in the form of co-creation of study materials and co-analysis), coupled with research team backgrounds in anthropology, public health, and oncology helped triangulate analysis by incorporating various types of expertise.<sup>18</sup>

This study followed all ethical standards for the conduct of human subjects' research. Interview transcripts were de-identified and stored securely in a password-protected server. This study was approved by the Vanderbilt University Medical Center Institutional Review Board (IRB # 220096).

## Results

In total 39 participants completed the eligibility survey. Of those individuals, 36 successfully completed a one-on-one semi-structured interview. Three individuals who completed the screener survey were unable to successfully schedule an interview due to non-response after three contacts from MLR. Of the 36 participants, 8 women were between the ages 30 and 45, 15 women were 46 to 59, and 13 women were 60 or older (Table 1). In terms of race and ethnicity, 28 women were white, 8 were women of color including Black, Latina, and Asian. Of the women interviewed, 21 had been living with MBC equal to or more than 5 years. The 36 participants described receiving care across 48 unique settings of which 26 mentioned locations were community cancer centers, 21 were academic medical centers, and one was a military hospital.

Phronetic Iterative Analysis showed the following major themes as connected to care experiences during the COVID-19 pandemic: (1) telehealth utilization, (2) disruptions to care, and (3) virtualization of social care.

### Telehealth Utilization

*Preference for and against telehealth utilization.* There was wide variability in preferences for and against telehealth. These preferences were determined by convenience and accessibility as well as by perceived ability to treat physical

**Table 1.** Participant Demographics ( $n = 36$ ).

<b>Race</b>	
White	28 (77.8%)
Women of color <sup>a</sup>	8 (22.2%)
<b>Age</b>	
30-45	8 (22.2%)
46-59	15 (41.7%)
60+	13 (36.1%)
<b>Years living with MBC</b>	
<5 years	14 (38.9%)
>= 5 years	21 (58.3%)
Unknown	1 (2.8%)
<b>Project Life Membership Length</b>	
<6 months	4 (11.1%)
6-11 months	9 (25.0%)
12-24 months	19 (52.7%)
Unspecified	2 (5.6%)
Could not remember	2 (5.6%)
<b>Cancer Center Type</b> ( $n = 48$ institutions)	
Academic Medical Center	21 (43.7%)
Community Cancer Center	26 (54.2%)
Military Hospital	1 (2.1%)

<sup>a</sup>Women of color includes participants who self-identified as Black, Asian, or Latina. Racial/ethnic distribution is presented in aggregate to protect participant confidentiality.

needs through in-person physical examination versus virtual evaluations. Concerning convenience, participants, who often lived far from oncology centers, pointed to telehealth as a practical option for avoiding long journeys to care. As one participant who received no telehealth said, “I did have my oncologist visits in person. But it was a little inconvenient because... we live a distance from where all of these things occur...” As another participant stated, “...utilizing Zoom like we’re doing now for appointments. I actually think it’s been a positive thing because of not having to drive all the way to the cancer center when I’m feeling lousy, and not in the mood to find a parking space, walk in, etc. I like having telemedicine visits...”

Convenience also included the accessibility of second opinions, which participants highly valued and took advantage of with or without telehealth. As one participant noted, “I did go to somebody pretty well known up in [city]. And so, I was able to get a phone consult very easily because of the situation with COVID. I didn’t have to go up to actually go see him. [...] And so that was nice.” Another participant expressed similar sentiments, “I took advantage [of telehealth] by having had a second opinion from the East Coast without having to travel there.”

Although, overall, participants pointed to telehealth as more convenient, some noted that there are occasions when it is more practical to have in-person appointments when already needing to be in-clinic. As one participant noted, “I was diagnosed with progression [...], and I have been seeing the [local] oncologist in person because I’m now receiving [...] injections. So, I have to go in once a month anyway. I’m driving an hour to get a shot [...] I might as well see the oncologist in person.”

Two primary reasons associated with a preference against telehealth were impersonality and the inability to assess physical needs. Impersonality arose in sentiments such as, “I’m not a fan [of telehealth], to be honest, I am a... I am a face-to-face consumer, I guess, when it comes to health care, and it felt impersonal.” When it came to the ability to assess physical needs, one participant stated, “I want to have that connection in person. She [primary oncologist] can’t examine me, right? It’s different talking and somebody actually laying hands on you.”

This statement alludes to two mediating factors that influenced participants’ preferences around telehealth: the kind of appointment and status of cancer progression. Participants preferred appointments centered around palliative care, psychological care, consultation, diagnostic test results, and non-physical check-ins to be virtual, while appointments that benefit from physical touch (such as physical examination with oncologists) were preferred to be in-person. Appointments demanding physical presence were more prominent for those experiencing progression. For instance, one participant who had progression noted still receiving in-person care while having an active COVID-19 infection: “I’ve had progression, and I got COVID... and I was in the middle of having SPRT stereotactic radiation. [oncology clinic] had this whole protocol where I would park in the garage. There would be this person covered in this yellow hazmat suit. They walk me into the radiation room. They walk me out.” This example of radiation treatment demonstrates the measures taken to ensure the continuity of care for treatment that, by definition, could not be moved to telehealth.

### Disruptions to Care

*Delays in care.* Delays in telehealth and in physical care due to COVID-19 appeared in forms such as trouble scheduling appointments, especially for diagnostics. As one participant stated, “There have been times that I have struggled to get appointments. For instance, I had significant progression recently. I needed to get a liver biopsy, and when I called to make the appointment, they gave me an appointment two months away.” Another participant stated similar delays when she said, “And in the midst of COVID, I also developed a back problem and ended up having to have a surgery, and all of my diagnostics were delayed because they didn’t have the personnel. Everything was shut down. They were doing no elective diagnostics. I couldn’t get my MRI. I couldn’t have my surgery until I had the MRI. So, it was several months that I went on with a whole lot of pain.”

Overall, however, delays in care were not a widely reported consequence of COVID-19 for participants. As one participant stated, “...I feel like things were more backed up because of COVID and everything. But overall, I didn’t have as hard of the time as other people with having to wait longer.”

*Isolation from caregivers.* Participants reported a strong feeling of isolation during in-person care. Specifically, regulations

concerning non-patient visitors inhibited caregiver accompaniment. One participant stated, “[oncology clinic] was very strict. Like, I had to go up by myself a few times. I couldn’t bring my husband or my daughter. You know, I should try to bring someone along to take notes and just be my second ear because of the severity of the discussions.” Another noted, “So, I was being treated and emotionally it was difficult because they restricted visitors, so people who were in treatment can only be there by themselves...” and one other participant added, “Having to walk into the cancer center by myself during the time of COVID, there are certain appointments where you just need somebody there.”

Such situations, where caregiver support was missing, coupled with other COVID-19 pandemic protocols created a feeling of isolation and fear. One participant noted, “I’d say it was scarier getting my scans done, walking in the hospital and not seeing a soul in the hallways, you know, and just the whole situation. I had that shortly after everything locked down.” As another participant said, “...everyone that came into my room looked like they were going to space because of all the PPE [personal protective equipment]. It drew a distinction between health care workers and the patient where you felt even more isolated and even more different. [...] With the doctors wearing masks I have felt more of a distance between me and my providers because you can’t see their whole face.” This example was a demonstration that in-person care without the presence of caregivers, and with the added stress of COVID-19 precautions, intensified already stressful, fearful, and isolating experiences of metastatic cancer care.

**COVID-19 infection.** Several participants personally experienced SARS-CoV-2 infection or had a household member become infected which disrupted in-person care through temporary cessation of oncology treatment. For example, one participant stated that due to a COVID-19 infection, “...I couldn’t see my oncologist or anybody because I couldn’t literally walk from my bed to the bathroom. I lost all my abilities to do that.” This participant also noted little virtual engagement from providers during this time, who, according to her, assumed she would die from her infection.

However, some individuals diagnosed with COVID-19 did not experience extreme disturbances to care. As one participant stated, expressing minimal disruption, “I mean, you know, I had to skip a treatment one time because I had COVID.” Further, as another participant noted, her MBC was detected only because of complications during the disruption that was her COVID-19 infection, “So I actually got officially diagnosed with stage four when I got COVID and got a pulmonary embolism... that was kind of nice, thank you COVID, I guess.”

### *Virtualization of Social Care*

**Support groups.** The majority of participants noted lack of integrated social support services for MBC patients at their

cancer centers during the COVID-19 pandemic. As one participant noted, “First of all, whenever I found out that I have metastatic breast cancer, I really wanted to talk to other people with the disease. And there were no support groups whatsoever in the entire [geographic] area, which is a pretty good-sized city. And it just amazed me and infuriated me that there were no support groups.”

In turn, patients were forced to supplement this piece of their care on their own, and during COVID-19, in-person outlets became more limited or impossible. Therefore, participants noted virtualization of their social support searching, which provided quality of life improvements. As one participant stated, “That’s actually one thing from COVID I’ve benefitted from... because everything has moved online. So, I’m participating in an online support group... I’ve found a couple that meet via Zoom where I can connect to people who understand my story and understand my situation.” The virtualization of social care such as support groups during the pandemic enabled greater communal connectivity at a time when physical connection was limited due to the pandemic.

### **Discussion**

To our knowledge, this is the first study to partner with a MBC community organization to understand how the COVID-19 pandemic has affected MBC care from the perspective of patients. The women represented in this study described varying experiences with telehealth utilization, disruptions to care, and virtualization of social care as three primary themes of navigating through a pandemic while living with, and being treated for, MBC.

During the early phases of the COVID-19 pandemic, the American Society for Clinical Oncology recommended telehealth visits for MBC care that did not relate to recurrence, progression, or emergencies.<sup>16</sup> The current study found that preference for telehealth varied widely by appointment type, length of time living with MBC, among other factors (such as progression status). As participants also made clear in this regard, improved coordination concerning appointment scheduling would play a part in such considerations through, for example, aligning in-person treatments like chemotherapy, radiation, or imaging with same-day in-person appointments or results sharing. Further, the possibility of telehealth to exacerbate inequities due to disparities in broadband and digital literacy must also be considered.<sup>20</sup> To meaningfully integrate telehealth as part of MBC care beyond the COVID-19 pandemic, patient-centered solutions to common implementation issues must be considered.

As concerns disruptions to care in the form of limited caregiver presence, participants’ narratives highlight the importance of enabling at-appointment caregiver supports for emotional wellbeing and disease navigation. The importance of having an additional presence to take notes during important appointments and procedures cannot be overstated, and such importance has been supported.<sup>21–23</sup> In facilitating

such in-person involvement, however, the complication emerges around precautions connected to COVID-19's risk for immunocompromised patients.<sup>24</sup> The current study noted such precautions present an added group of stressors to an already stressful illness and care experience. Therefore, clinics should continue to strive for a balanced approach in infectious disease prevention and in-clinic social supports that help prevent the exacerbation of the already stressful experience of MBC treatment.

Finally, the virtualization of social care highlights important considerations and potentially presents an area of major opportunity for innovating in supportive care delivery. In this study, participants stressed repeatedly the need to be connected to such resources and having to find such resources themselves virtually due to pandemic-related protocols. Such gaps at the point of care pre-pandemic have been previously described in curated social media chats centered on MBC.<sup>25</sup> The findings represent an opportunity to learn from patient-led virtual initiatives that have filled in major supportive care gaps during the COVID-19 pandemic.

### Strengths and Limitations

This study benefits from a large sample size of qualitative interviews with great depth that included substantial diversity in the MBC experience. Participants in this study spanned different age ranges, races, care settings, and time living with MBC. Additionally, the study's triangulated analysis had transdisciplinary, analytic input from an MBC patient organization's leadership, a public health policy professional, a radiation oncologist, and a medical anthropologist.

This study is limited in that all participants were, by definition, members of an online support group and, therefore, have high digital literacy as well as a higher likelihood of having experienced increased connectedness and social support during the COVID-19 pandemic. The insights gained from these participants, particularly around perceptions of telehealth may not apply to those living with MBC who are not engaged in such online communities.

### Conclusion

Given individually patterned preferences for telehealth, clinicians should consider individual-context specific telehealth utilization to better empower patient agency and to remove patient burden. With the perceived negative disruption on wellbeing of not having caregivers present at appointments during COVID-19 precautions, clinics should consider striking a balance between infectious disease prevention and caregiver presence to not exacerbate the already stressful experience of MBC care. Finally given the positive effects of virtual social supports, especially in light of COVID-19's impacts on in-person gatherings, cancer centers should support the integration of such services while insurance companies should financially support the coverage of such services' charges.

### Authors' Contributions

Dr Roberson and Mr Woods had full access to all the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis.

*Concept and Design:* Roberson, Glenn, Maues, James.

*Acquisition, Analysis, or Interpretation of Data:* All Authors.

*Drafting of Manuscript:* Roberson, Woods.

*Critical Revision of Manuscript:* All authors.

*Statistical Analysis:* Roberson, Woods.

*Administrative, Technical, or material support:* All authors.

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The funding sources had no role in the design and conduct of the study; collection, management, analysis, and interpretation of the data; preparation, review, or approval of the manuscript; and decision to submit the manuscript for publication.

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