

Impact of the COVID-19 Pandemic on Patients' Experiences with Cancer Care



The COVID-19 pandemic has severely impacted cancer patients as they are at increased risk of infection because of a compromised immune system and of serious illness if they develop COVID-19.¹ The pandemic also has disrupted oncology care, resulting in treatment delays and changes to care plans.^{2,3,4,5}

To learn more about these issues, we conducted a study with cancer patients to understand their experiences with cancer care during the pandemic. We addressed the following research questions:

- How has patients' cancer care been impacted by the COVID-19 pandemic? What kinds of delays and disruptions do they experience?
- What are patients' experiences with telehealth? How do patients experience communication with their doctors and other healthcare professionals via telehealth as compared with face-to-face communication?
- Are patients getting the information they need and want about COVID-19 from their doctors and other healthcare professionals?
- What are patients' concerns related to social isolation and support?

At a Glance

The COVID-19 pandemic has severely impacted cancer patients, who are at increased risk of infection and severe illness.

To understand patients' experiences with cancer care, we conducted an online survey and virtual focus group discussions.

67% of patients reported disruptions or delays in care due to the pandemic.

One of the biggest changes to their cancer care was that patients could not bring a support person with them to appointments and chemotherapy sessions.

Patients also had appointments switched to telehealth, changing the way they communicate with their doctors.

42% of patients had discussed their risk of getting COVID-19 with their doctor and 40% had discussed ways to reduce their risk.

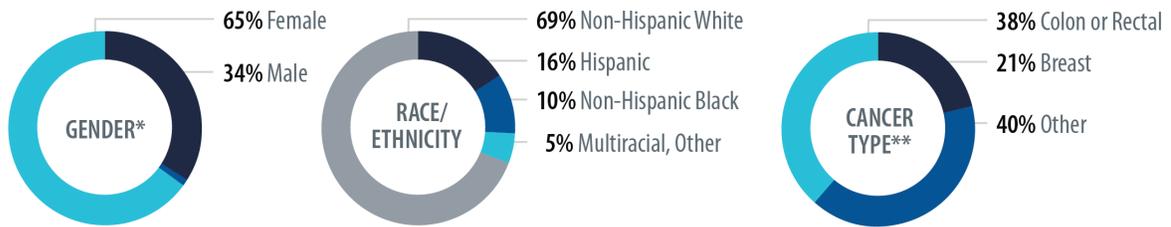
37% of patients were seriously or very seriously concerned about not seeing family or friends as much as usual because of the pandemic.

A patient-centered communication approach can help patients understand adjustments in their care, cope with difficult feelings, and manage the uncertainties of treatment during the pandemic.

Methods

We conducted an online survey (N=317) and virtual focus group discussions (FGDs; N=19 participants) with cancer patients. The survey was conducted from October to December 2020 and the FGDs were conducted from November 2020 to January 2021. To be eligible to participate, patients had to be diagnosed with cancer (any type), aged 18 or older, and have received cancer treatment in 2020. Survey respondents and FGD participants were recruited through two partner organizations—the Cancer Support Community and Fight Colorectal Cancer—and a research recruitment firm. Characteristics of survey respondents and FGD participants are shown in **Figure 1** and **Figure 2**, respectively.

Figure 1. Characteristics of Survey Respondents (N=317)

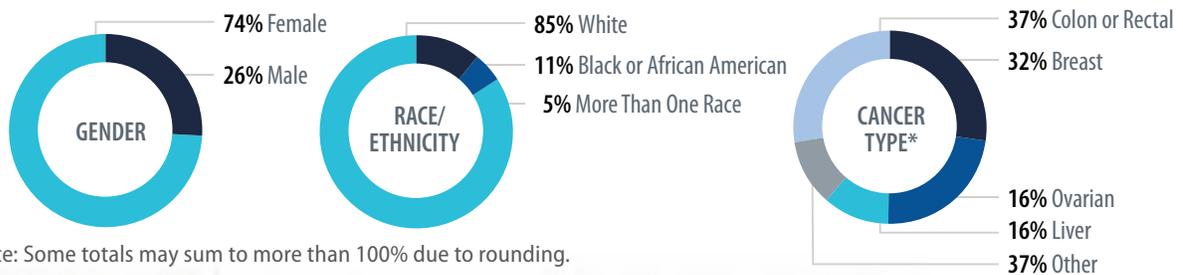


Note: Some totals do not equal 100% due to rounding.

*Other gender or preferred not to answer <1%.

**Most recent diagnosis.

Figure 2. Characteristics of Focus Group Discussion Participants (N=19)



Note: Some totals may sum to more than 100% due to rounding.

*Could select more than one cancer type.



Findings

Disruptions, Delays, and Changes to Treatment Plan

Overall, about 67% of survey respondents reported disruptions or delays in care. About half of respondents said that some appointments had been changed to telehealth and others said that treatment was delayed (27%) or appointments were delayed, cancelled, or rescheduled (24%). Additionally, respondents said there had been changes to their treatment plan (14%), treatment frequency (17%), and type of treatment (15%), such as change from IV chemotherapy to oral chemotherapy.

"I was getting a scan and there was a spot that had come up on my liver. I ended up having to wait a month to see my oncologist for them to read it. I was calling to try and get answers.... When you get those scans, you're just a nervous wreck."

– Focus group discussion participant

"It was disappointing that one of my surgeries was delayed. And then I was very worried about another one of my surgeries this year being delayed and that added a lot of stress... the rules change each day."

– Survey respondent

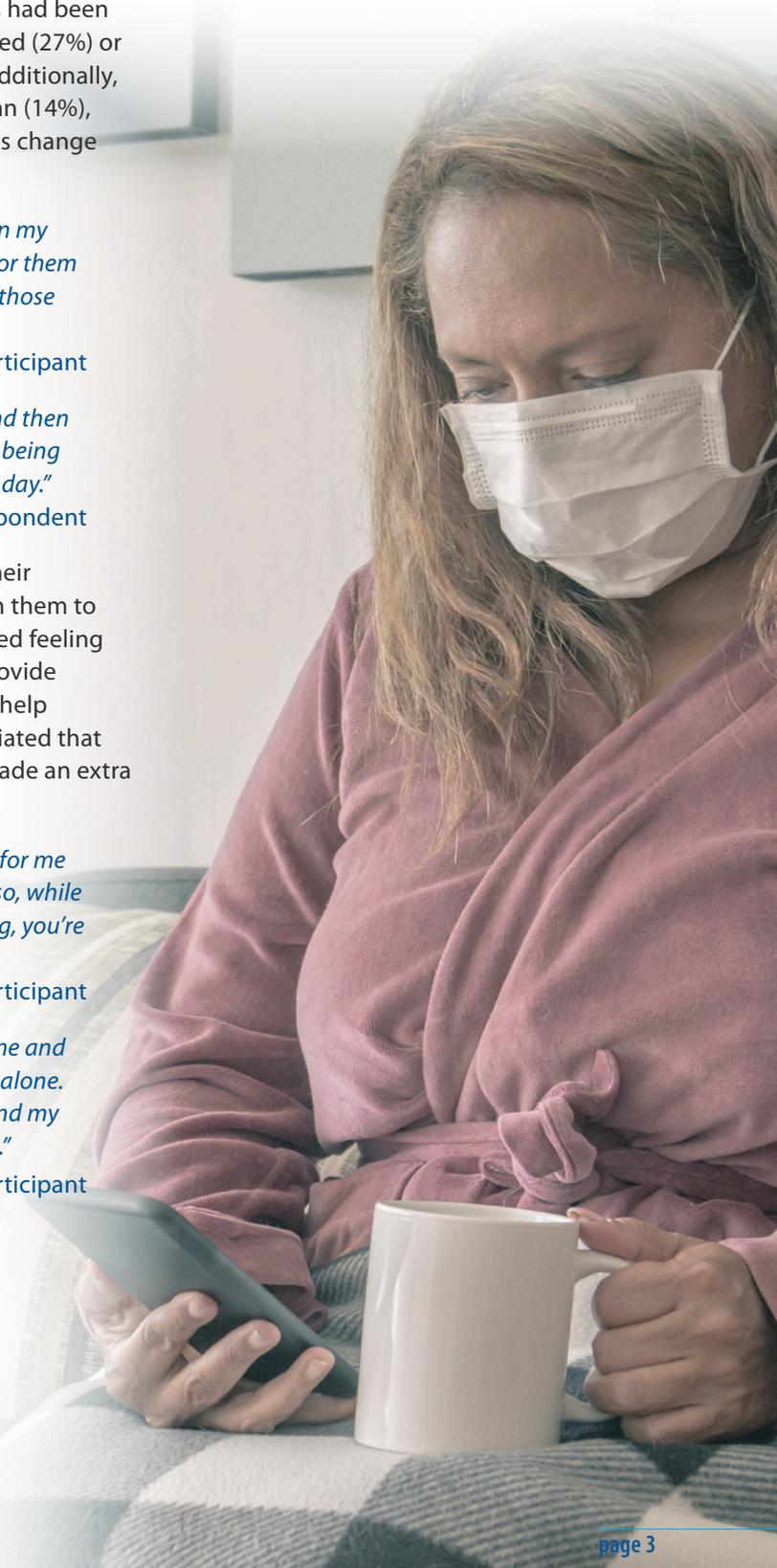
FGD participants reported that one of the biggest changes to their cancer care was that they could not bring a support person with them to appointments and chemotherapy sessions. Participants described feeling alone, vulnerable, or scared. They missed having someone to provide emotional support and having "an extra set of eyes and ears" to help process information and ask questions. Participants also appreciated that nurses and staff were sensitive to how alone patients felt and made an extra effort to show caring and support.

"Your support system is so important, and taking that away ... for me personally, has been the worst part of the whole process. And so, while the people at that Center were absolutely wonderful and caring, you're still going there alone."

– Focus group discussion participant

"My husband is not allowed to come into appointments with me and that is very frustrating. I've had to do my last rounds of chemo alone. I felt very isolated and alone and depressed. I had the nurses and my oncologist, but your significant other is a huge support system."

– Focus group discussion participant



Experiences with Telehealth

About 7 out of 10 survey respondents had at least one telehealth appointment for cancer care. We asked respondents about communication with their doctors and other healthcare professionals via telehealth as compared with communication in person, as shown in **Figure 3**. We found significant differences across some respondent subgroups. Respondents who were male, Hispanic, and younger were more likely to say that their doctors communicate better via telehealth than in person (data not shown).

Figure 3. How Survey Respondents Compare Telehealth Communication with In-person Communication



FGD participants shared a range of views about telehealth, as shown in **Table 1**. Some participants preferred telehealth visits for the convenience of being able to stay in the safety and comfort of their own home. Participants also liked that they could multitask at home while waiting for the doctor rather than having to drive (in some cases, very long distances), go through COVID safety procedures, and be alone in a waiting room. Another advantage of telehealth was that family members can easily join. However, some participants thought telehealth was less personal and it was more difficult to build rapport. Others said telehealth worked well if they already had an established relationship with their doctor. Some participants were concerned that their doctors could not assess them physically during telehealth visits.

Table 1. Focus Group Discussion Participants' Perceptions about the Advantages and Disadvantages of Telehealth

Advantages	
Convenience and comfort of home	<i>I actually enjoy tele-visits. It consumes less time and keeps me safe! Doctors tend to stay on schedule easier. – Survey respondent</i>
Family members and loved ones can easily participate	<i>I started to like telemed. I adapted. I would have my husband around the table, my oldest son, who is in nursing school who would sit there and he would just absorb everything. – Focus group discussion participant</i>
Safer during pandemic	<i>Telehealth is working during this tough time. It's not as great as in-person appointments but it keeps me safe. – Survey respondent</i>
Disadvantages	
Harder to build rapport, impersonal	<i>It's been difficult to continue to build rapport through telehealth. Communication doesn't just take place through verbal means and it's often those nonverbal parts of communication that help us connect and find comfort. – Survey respondent</i>
Absence of comforting touch	<i>I'll reference back the hug that my oncologist always gave me and how I miss that. It's kind of an isolating feeling right now. You're already maybe nervous about the pandemic and contracting it [COVID-19], and the "what ifs" if you do because of your cancer status. And then at a time when I really feel like I need a hug sometimes the most, it's not there. – Focus group discussion participant</i>
Lack of physical assessment	<i>There is something about being in and seeing your doctor face-to-face.... It just sets you more at ease. You're there. They can see you. If you're like, "Oh, I have this pain here," they can touch your liver and be like, "Oh, that's this." – Focus group discussion participant</i>

Patients' Discussions with Healthcare Professionals about COVID-19

We asked survey respondents whether they had discussed various COVID-related topics with their doctors or other healthcare professionals. About 42% had discussed their risk of getting COVID-19 and 40% had discussed ways to reduce their risk. Fewer had discussed other topics, including getting tested (28%), what would happen if they got infected (20%), or other COVID-related worries or concerns (9%).

We also asked survey respondents if they got the information about COVID-19 they needed in their conversations with their doctors and other healthcare professionals. About 8 of 10 respondents who had discussed COVID-19 with their doctors (and answered a follow-up question) felt positive about these conversations. Others said their doctors shared only "very basic information" that was not specific to their situation. However, they also understood that many unknowns remain about COVID-19. **Table 2** presents example comments of survey respondents regarding meeting their information needs.

Table 2. Survey Respondents' Comments about Having COVID-19 Information Needs Met

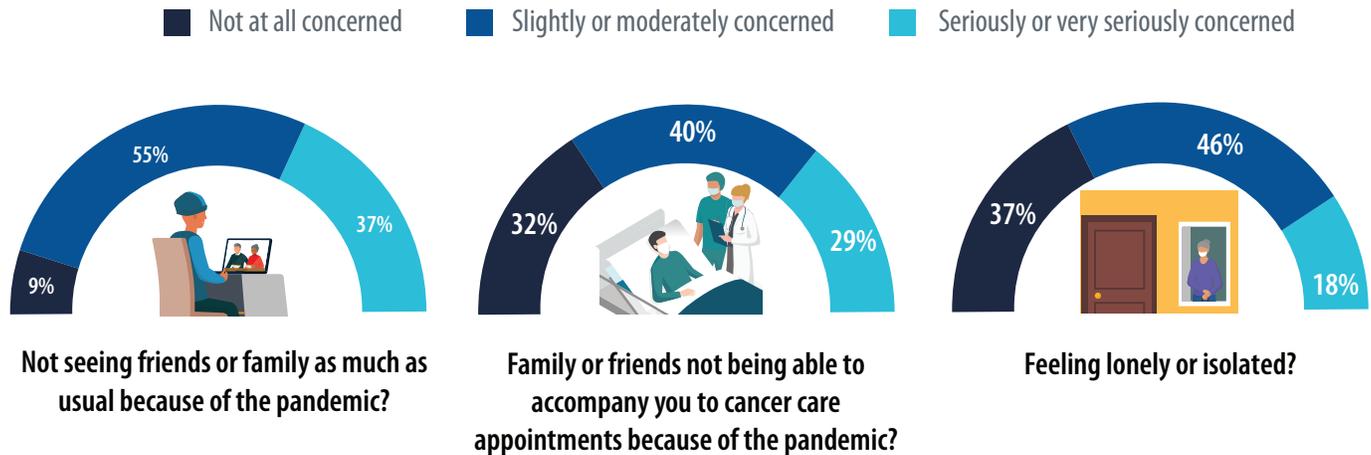
Respondents reporting their information needs were met	Respondents reporting they wanted more information
<i>I was told what I could do and should not do to reduce my risk. I was also told how it [COVID-19] would probably affect me since I have lung cancer.</i>	<i>I got very basic information, the same as on social media. I would prefer information specific to me.</i>
<i>My doctor answered all my questions about what would happen to my treatment if I got it.</i>	<i>Not really. I was told that the virus was too new for them to know if my hormone suppression therapy would compromise my immune system.</i>
<i>My doctor explained the process of getting testing, what to do if I tested positive, and how I should stay home and avoid crowds.</i>	<i>Obviously, there is a lot of uncertainty regarding COVID. My doctor explained his opinion about my level of risk.</i>



Concerns about Social Isolation and Lack of Social Support

Among survey respondents, 37% were seriously or very seriously concerned about not seeing family or friends as much as usual because of the pandemic. Other serious or very serious concerns were family or friends not being able to accompany them to cancer care appointments because of the pandemic (29%) and feeling lonely or isolated (18%), as shown in **Figure 4**.

Figure 4. Survey Respondents' Concerns about Social Isolation and Lack of Social Support*



*Percentages sum to more than 100% due to rounding.

FGD participants shared feelings of being overwhelmed by dealing with the pandemic in addition to their cancer diagnosis. One participant expressed that “the idea of catching something like this [COVID-19] after you’re fighting something like cancer, it’s just really overwhelming to even think about.” In general, they want their doctors to be sensitive to the emotional toll of the situation of undergoing cancer treatment during the pandemic. One participant shared the following:

“During this time, the doctors need to be really mindful of how nervous their patients are and how overwhelmed we are and how depressed we might be getting. Because on so many levels, it is just a recipe for becoming depressed, being sick with a terrible disease and being afraid of this COVID and being alone and isolated.”

– Focus group discussion participant



Discussion and Recommendations

This study highlights the uncertainties and stress for patients receiving cancer treatment during the COVID-19 pandemic, as they have had to adjust to disruptions in care, not having loved ones with them during in-person appointments, and changes in how they communicate with their doctors as many appointments are being conducted via telehealth. Most survey respondents were as satisfied with communication in their telehealth appointments as they were with in-person appointments, although these perceptions varied by patient subgroup.

In these circumstances, a patient-centered communication approach that helps provide high-quality, patient-focused cancer care is critical.⁶ Patient-centered communication can help patients understand what the pandemic means for them—such as their risks—and manage the uncertainties of their diagnosis and treatment in the context of the pandemic. Study participants stressed the importance of healthcare professionals acknowledging and validating patients' concerns and fears. They also emphasized the importance of healthcare professionals being aware of patients' need for social support given they are more isolated when receiving treatment during the pandemic.

Further research is needed to understand the reasons underlying differences in preferences for telehealth communication as compared with face-to-face communication across different patient subgroups.



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More Information

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