



# How did women with breast cancer experience the first wave of the COVID-19 pandemic? A qualitative study

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## Abstract

**Objective** The ongoing COVID-19 global pandemic is a stressful experience that is particularly likely to negatively affect cancer patients. The goal of this qualitative study was to explore how breast cancer patients experienced the first wave of the COVID-19 outbreak.

**Methods** As part of a larger study, 23 women accepted to take part in an individual phone interview investigating the psychosocial consequences of the COVID-19 pandemic.

**Results** The hybrid inductive-deductive thematic analysis revealed the following themes: (1) increased general psychological distress; (2) concerns about the impact of treatment-related immunosuppression (i.e., increased risk of catching the SARS-CoV-2 and of developing more severe complications); (3) higher risk of catching the SARS-CoV-2 in the hospital; (4) possible impact of changes in cancer care trajectory on prognosis; (5) distress related to going to treatment alone; (6) social isolation and decreased family relationships; (7) increased responsibility at home; (8) variety of coping strategies used (i.e., adherence to public health measures, seeking professional help, avoidance); (9) difficulty receiving professional mental health services and social support; (10) anxiety related to return to work; and (11) uncertainty about the future.

**Conclusions** The COVID-19 outbreak is a major medical, psychological, social, and occupational stressor for women undergoing treatment for breast cancer. We offer recommendations to reduce the impact of subsequent waves of COVID-19 and other epidemics in this population.

**Keywords** Cancer · COVID-19 · SARS-CoV-2 · Epidemic · Qualitative analysis

The ongoing COVID-19 global pandemic has been a stressful experience for everybody. One group that is particularly susceptible to experiencing psychological distress in relation to this unique event is cancer patients. Indeed, because many of them are immunosuppressed by their malignancy and cancer treatment (e.g., chemotherapy), they are at a greater risk of infections and have been therefore identified as a high-risk population to contract the SARS-CoV-2 and to have more complications and thus, a poorer prognosis [1, 2, 16, 23, 25]. In this context, receiving cancer treatment in a hospital

where COVID-19 cases are treated may have been highly stressful. In addition, because of confinement and physical distancing measures lasting for several weeks, a sense of isolation and diminished social support are likely to have occurred. Finally, hospitals implemented several organizational changes to better respond to the influx of COVID-19 cases including an offloading of many cancer care activities. This includes cancelation and postponement of elective and non-urgent cancer surgeries and medical tests, as well as changes in treatment protocols (e.g., longer intervals between chemotherapy cycles). Not knowing whether these delays and changes in cancer care could have an impact on their prognosis must have been highly distressing as well. However, these are all assumptions that need to be confirmed through research.

A first qualitative study was published [13], which aimed at characterizing the behavioral and psychosocial responses of 15 patients with advanced lung cancer to the COVID-19 pandemic. The investigators analyzed the spontaneous comments

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on the pandemic given by participants during follow-up interviews for a study on hope, goals, and psychological well-being conducted between March 20 and May 8, 2020. Six themes emerged from the qualitative analysis: (1) cancer remained their main concern; (2) mixed feelings about some COVID-19 policies (e.g., no visitors); (3) awareness that COVID-19 posed an additional threat of mortality for them and that they were at an increased risk for poor outcomes if they were to contract it; (4) behavior changes (with some endorsing public health guidelines with greater intensity) and fear and frustration (with some reporting increased anxiety and depressive symptoms and loneliness, especially the unpartnered); (5) sense of loss/mourning for the things that the COVID-19 pandemic had taken from them in addition to what cancer had taken; and (6) positive reinterpretation of cancer and the pandemic and greater appreciation for life. Although these findings are highly informative, it is important to gain a better understanding of patients' experience by using an interview that specifically focuses on the COVID-19 outbreak and in patients with other types of cancer and that have a better prognosis.

The goal of this qualitative study was to explore how breast cancer patients experienced the first wave of the COVID-19 outbreak.

## Methods

### Participants and procedure

When the COVID-19 outbreak began, we were conducting a longitudinal study on the role of perfectionism on breast cancer patients' psychological adjustment. We were authorized by the ethics committee of the CHU de Québec-Université Laval to continue taking measures from our accrued participants and to solicit them to participate in a substudy on the psychosocial impact of the COVID-19 pandemic. Among the 39 participants contacted, 36 agreed to participate. They were first invited to complete an online questionnaire on stressors related to the COVID-19 pandemic developed by our research team. Results of this quantitative study are presented elsewhere [14]. At the end of the questionnaire, participants were asked if they agreed to take part in an individual phone interview that asked further questions on their experience related to the pandemic. Twenty-three of them agreed to do so. None of the participants had developed COVID-19 at the time of the interview.

Inclusion criteria for the main study were: (a) non-metastatic breast cancer, (b) be scheduled to receive chemotherapy, (c) between 18 and 80 years of age, and (d) able to read and understand French. Exclusion criteria were: (a) metastasis, (b) have received chemotherapy in the past, (c) severe cognitive impairment (e.g.,

Alzheimer's disease), and (d) severe psychiatric disorder (e.g., psychosis, bipolar disorder).

The study was conducted in Quebec City, Quebec, Canada, where the shutdown and lockdown began on March 13. Interviews took place between May 12 and 22, 2020. The Quebec province was considered to be the epicenter of the COVID-19 pandemic in Canada, accounting for about half of the cases at the time of the study.

### Measure

The semi-structured interview included the following questions:

- 1) How are you currently experiencing the coronavirus pandemic?
- 2) What are your main sources of concern and stress about this situation?
- 3) How is the current situation affecting your psychological and physical health? For example, have you noticed any changes in your mood, morale, your anxiety and stress levels, your sleep, and your ability to concentrate? How would you describe these changes? How are they currently affecting your life?
- 4) At what point were you in your cancer trajectory when the pandemic began in Quebec?
- 5) Were there any changes made to your care trajectory as a result of hospitals getting ready for the pandemic? Were you sufficiently informed about these changes? Was there any professional available for you to contact about this? If your treatment continued, how do you feel about having to go to the hospital for your treatments during this time of pandemic?
- 6) Do you have anything to add about how the pandemic has impacted your life?

### Analysis

All interviews were audio recorded and transcribed verbatim by an undergraduate student. Verbatim transcriptions were imported in NVivo 12.0, and a hybrid inductive-deductive thematic analysis was performed by two doctoral students in psychology (CB and AJT; Fereday & Muir-Cochrane, 2006). First, each rater read and coded the same three verbatim transcriptions and developed a common initial coding manual using a shared document. Then, they met to discuss, resolve inconsistencies, and modify the coding manual accordingly. Following this, they divided between them the remaining verbatim transcriptions and coded them. New themes were added to the coding manual when appropriate.

## Results

### Demographic characteristics

Table 1 presents participants' socio-demographic data. On average, patients were 51.8 years old, were mainly married or in a committed relationship (69.6%), and were highly educated with 52.1% having a university degree. Participants took part in the interview either during (26.1%) or after the completion of their chemotherapy treatments (73.9%).

### Themes identified

#### Increased general psychological distress

A majority of participants experienced increased anxiety as a result of the COVID-19 pandemic. The level of anxiety varied among individuals, from having more concerns than usual to having severe anxiety. Some participants also reported having sleep difficulties and mood swings associated with the pandemic.

“I’m not the kind of girl who suffers from anxiety in life. I’m the associate general manager of an accountancy group, I’ve always been under stress. Since the pandemic began I feel I have this ball of anxiety... in my

stomach. My family doctor is treating me for this and she prescribed some medication to try to control it.”

“Yes. I even almost thought at a certain point that I was suffering from depression. I was apathetic, I would cry a lot over nothing. The lockdown, at the beginning, that was very hard. Really.”

**Concerns about the impact of treatment-related immunosuppression** The majority of the participants were very concerned about catching the SARS-CoV-2 and about developing severe complications as a result of their treatment-related immunosuppression. Public health officials advised immunosuppressed people to leave their homes as little as possible and to be extremely careful. It was one of the most important concerns reported by the participants.

“Sure if I ever catch the disease, now that my immune system isn’t that strong... but getting sick, sure that’s what worries me. I also wouldn’t want to get sick.”

**Higher risk of catching the SARS-CoV-2 in the hospital** Some participants did not have to stop their cancer treatment. This was a relief for them. On the other hand, they had to face the

**Table 1** Characteristics of participants ( $N = 23$ )

Characteristics	<i>M</i> (SD)	<i>N</i> (%)
Age (years; range: 37–71)	51.8 (10.3)	
Time since cancer diagnosis (months; range: 4–13)	8.2 (2.6)	
Marital status		
Married/cohabitating		16 (69.6)
Single		3 (13.0)
Separated/divorced/widowed		4 (17.3)
Education		
High school or less		6 (26.1)
College		5 (21.7)
University degree		12 (52.1)
Current occupation		
Working (full/part time)		5 (21.7)
Sick leave		10 (43.5)
Retired		5 (21.7)
Unemployed		2 (8.7)
Annual family income (CAD)		
Less than \$20,000		1 (4.3)
\$20,001–\$60,000		6 (26.0)
\$60,001–\$100,000		4 (17.3)
\$100,001–\$140,000		5 (21.7)
\$140,001 and more		5 (21.7)
Do not know or refused to answer		2 (8.7)

stress of having to go to the hospital during a pandemic. Most felt reassured by the sanitary measures put into place in the hospitals. But some were concerned about other cancer patients. They feared that patients were so eager to receive their treatment that it might be tempting not to reveal if they had COVID-19 symptoms or if they had been in contact with anyone who had the disease.

“Sure, you go there, everything to protect you is already in place and there are people who remind you and ask you questions regularly. I have no problem with that. But I don’t know about the other people I meet, other sick people who were going in for treatment, you tell yourself, I hope nobody is hiding anything. You know, you never know. So, sure, I was thinking about it... when I touched the elevator button, I used the edge of my coat to have as little contact as possible. Whether you like it or not, that’s always in the back of your mind, that’s for sure.”

**Possible impact of changes in the cancer care trajectory on cancer prognosis** The participants experienced a great amount of anxiety related to changes in their care trajectory. Some had their treatments delayed, while for others, routine follow-up visits were canceled. They feared that such changes could negatively impact their prognosis and reduce the likelihood that a cancer recurrence would be detected in time.

“I was more stressed out about choosing either to have COVID-19 or to have my cancer come back because it wasn’t being treated. That was my stress. It was more like I’m choosing between which of the two ways I want to die.”

“It was hell. I had the impression I was waiting to...that I was giving free rein to the disease to progress. That really wasn’t any fun.”

**Distress related to going to treatment alone** For a number of participants, it was very difficult emotionally to go to their treatments alone, which was a requirement during the confinement.

“What bothered me most was having to go all alone. Usually my husband comes with me to all my appointments. If not, then my mother-in-law. I’ve never gone alone. They aren’t allowed to come, so I have to go alone all the time.”

**Social isolation and decreased family relationships** The participants expressed that their confinement was very stressful

for them. Many of them were already in some kind of social isolation and were restricting their outings and their contacts with family and friends because of the chemotherapy they were receiving. Hence, for them, the pandemic had the effect of extending and aggravating preexisting social isolation measures. Indeed, it was advised by public health officials that people with a weakened immune system should not see their families at all. Some participants found it very difficult to get through cancer without their loved ones.

“Isolation, for me it’s already been since...already since Christmas that I haven’t seen my family because I was receiving chemo. So that adds a period...I was hoping to be able to see more of my loved ones again after my treatments were over, then you add the lockdown. I can tell you we began lockdown before everyone else. It doesn’t stop.”

“Sure I see them (my loved ones) but from a distance. You can’t hug them. You don’t have any human contact. That’s very hard. When you’ve been sick, human contact is very important, very, very important.”

**Increased responsibilities at home** Several participants reported having more responsibilities at home because of the pandemic, which was a significant stressor for them. Having extra cleaning to do was the task that participants talked about the most. In Quebec, the authorities advised people to wash groceries and anything else that came from outside the house (e.g., mail, packages, take-out food). Distance learning and increased child care also added to the burden of those who were parents of school-aged children, as all elementary and secondary schools were closed.

“Well...when my daughter comes home from work, I make sure she does everything so that she doesn’t give us the virus. So I make sure she gets undressed, that she takes her clothes to the washing machine, that she washes herself right away. When she brings things home, I disinfect them. I also disinfect everything that comes into the house. I have more responsibilities.”

“It’s no longer there because the kids are back in school. I am a perfectionist, so if the teachers give an assignment, I feel I have to do my best... That puts pressure on me, gives me stress. I wasn’t able to do everything, so I felt disappointed with myself that I couldn’t help my kids finish everything on time. That just wasn’t possible. With cancer and the treatments. I have a house to take care of.”

**Variety of coping strategies used** In order to adapt to the new stressors caused by the pandemic, participants used

various coping strategies. The most commonly used strategy was to follow public health recommendations, i.e., to stay home as much as possible, to wear a mask when in indoor public spaces, to wash their hands often, and to practice physical distancing. Also, some participants felt the need to consult a mental health professional while others used avoidance coping; they preferred to avoid talking about the pandemic too much so as not to think about it constantly. These same participants also stopped watching the daily press briefings by the prime minister informing the population about the daily number of infected cases and deaths, as well as changes in public health recommendations to adhere to.

“I really don’t go out that much, but if I go out, the others get more stressed than me. I put on a mask, I wash my hands, I have disinfectant wipes if I have to touch something.”

“Now I’ve stopped watching press conferences, I don’t watch them anymore... Otherwise, if you listen to that...it’s just a source of frustration and anxiety.”

**Difficulty receiving professional mental health services and social support** Some participants had to discontinue their follow-ups with their social worker or their physiotherapist, while others were no longer able to receive help at home from family and friends or from public services, which was a major stressor for them.

“It’s better now because I’ve completed my chemotherapy, but during the chemo, at the beginning, my mother-in-law was helping me. But then she couldn’t...come and help me...That put a bigger burden on the shoulders of my children, my husband and myself. It was a little tough, but now that my chemo is over, it’s all right. I’m able to do what I have to do.”

**Anxiety related to return to work** Just the thought of having to return to work in the context of a pandemic made some participants very anxious. Indeed, having to adapt to new health measures at work or to telecommuting were perceived as major stressors.

“Going back to work, that’s a big step. I don’t know when [that will be], from the stage we’re in right now, it’s still uncertain. But that adds a stress factor, how to go back to work in a situation like the one we’re in.”

**Uncertainty about future** Some participants were worried about their life in the future, whether they would be able to

start living again as they did before or whether they would have to be hypervigilant until the discovery of a vaccine.

“Well, with COVID my impression is that I’ll have to wait [self-isolate] until they find a vaccine. There’s a lot of uncertainty around that. I really don’t know what my life will be like.”

## Discussion

The goal of this qualitative study was to document the psychosocial difficulties experienced and challenges encountered by non-metastatic breast cancer patients during the first wave of the COVID-19 pandemic. Our findings are in line with those of Hyland and Jim’s study [13] conducted in patients with advanced lung cancer in showing that patients reported significant anxiety related to their higher risk of contracting the SARS-CoV-2, due to their immunosuppression, and to the possibility of suffering from more complications if they were to catch it. Also, consistent with Hyland and Jim’s findings, some patients experienced significant psychological distress (e.g., depressed mood, anxiety, sleep difficulties, loneliness) related to the pandemic. Physical distancing measures, which our participants seemed to strongly adhere to, were particularly difficult from an emotional standpoint given that it extended the duration and aggravated the intensity of the social isolation they were already experiencing because of their cancer treatment (i.e., chemotherapy). Overall, this suggests similar experiences whether patients are treated for localized or advanced cancer and regardless of cancer types, although comparative studies are needed before concluding this.

Our results identified additional problems that patients faced during the early pandemic. Some patients experienced a great deal of anxiety because of massive hospital offloading, which resulted in delaying their treatments. Many patients also reported that their follow-up medical visits had been canceled, which was another significant stressor for them given the likelihood that this could delay the detection of a potential cancer recurrence. In both situations, patients expressed fear of the impact these changes could have on their prognosis. This is consistent with results by Swainston et al. (2020) showing that breast cancer patients who experienced a disruption in their cancer care due to the COVID-19 pandemic had higher levels of psychological distress. Even though patients were relieved when no changes were made to their treatment protocol, they still experienced significant anxiety because of the risk of contracting the SARS-CoV-2 at the hospital when coming for their treatment. Some mentioned that it was difficult for them to trust that other patients would reveal having

COVID-like symptoms or having been in contact with a COVID-positive person just to make sure they received their treatment as planned, thus putting other patients at risk.

Our participants also discussed the increased workload (e.g., cleaning) at home due to the pandemic as another thing that was difficult. More particularly, school closures at the beginning of the pandemic, with schools having variable capacities to offer distance learning, put extra educational responsibilities on the shoulders of mothers of school-aged children. This effect was also observed among women in the general population [7, 11] but can become even more burdensome for women physically affected by the side effects of cancer treatment (e.g., fatigue).

Our study also showed that patients had an increased need for social support and professional services at a time when they actually had less access to some of these. Indeed, their social support from family and friends was reduced due to physical distancing measures and because some health care professionals (e.g., psychologists, social workers) had to temporarily interrupt delivering care because they did not have the equipment and facilities to provide telehealth services or were assigned to other tasks.

Finally, our study participants expressed considerable anticipatory anxiety related to their eventual return to work and their future in general. Returning to work is already a major stressor for patients who have received treatment for breast cancer [3, 15]. Having to go back to work during a pandemic, to adapt to new public health measures, to have to use public transportation, and to face the risk of contracting the SARS-CoV-2, was perceived as significantly adding to this stress.

Based on our results, we have come up with a few recommendations for stakeholders to better manage subsequent waves of the COVID-19 pandemic and other pandemics. First, we think that cancer care, including screening and treatment, should be considered essential services and under no circumstances be offloaded. This would avoid adding significant anxiety for patients receiving cancer care who already have to deal with a great deal of uncertainty. Moreover, delaying cancer treatment is likely to negatively affect patients' prognosis [4, 5, 18].

In addition to contributing to a general feeling of loneliness, our study revealed that going to the hospital alone to receive treatment was another significant negative effect of physical distancing measures. A second recommendation would then be to have less strict policies with regard to the possibility of being accompanied when receiving cancer treatment at the hospital, especially when patients come with a caregiver living with them.

Third, we think it is crucial to provide all mental health care providers with the equipment (computer, camera, individual videoconferencing license) needed to offer telehealth consultations. Indeed, this alternative delivery format has been shown to have equivalent efficacy with

face-to-face interventions for various psychological disorders, including in cancer patients [6, 12, 21]. This is not only relevant in periods of epidemics but also in order to increase access to mental health services for patients living in rural and remote areas who are typically underserved [24]. Yet, before the COVID-19 pandemic, telehealth had been slow to be implemented in mental health care [9, 24]. While video-based telehealth was implemented rapidly in the early pandemic in some facilities providing medical cancer care [10, 17] and mental health services [8, 19], we found no data specifically on the rate of redeployment of psycho-oncology services to telehealth. However, reports of experiences in psychiatric departments and mental health services have pinpointed significant disparities in terms of access to digital mental health care related to older age and geographical (e.g., no access to broadband), financial (e.g., not owning a computer or smartphone), technical (e.g., lack of comfort with technology), and language barriers [20, 22]. Hence, other modalities should be offered as well including telephone-based interventions and in-person appointments when telehealth is not possible or desirable.

While the high participation rate (92.3%) among women who were approached to take part in this secondary study is a strength, the study is not without limitations. First, these participants were compliant with the larger primary study on perfectionism and may not be representative of all women treated for non-metastatic breast cancer. Second, findings may not generalize to patients with other types of cancer, men, and those with a more advanced illness.

**Author contribution** Conceptualization (Josée Savard, Véronique Massicotte); methodology (Josée Savard, Véronique Massicotte, Catherine Banville); formal analysis and investigation (Josée Savard, Adèle Jobin-Théberge, Catherine Banville); writing, original draft preparation (Josée Savard, Adèle Jobin-Théberge); writing, review and editing (all authors); funding acquisition (Josée Savard, Véronique Massicotte); resources (Josée Savard); and supervision (Josée Savard).

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**Data availability** N/A.

## Declarations

**Ethics approval** The larger study was approved by the research ethics committee of the CHU de Québec-Université Laval (#2020-4579).

**Consent to participate** All participants provided a written informed consent.

**Consent for publication** N/A.

**Conflict of interest** The authors declare no competing interests.

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