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"I have cancer during COVID; that's a special category": a qualitative study of head and neck cancer patient and provider experiences during the COVID-19 pandemic

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Abstract

Purpose The COVID-19 pandemic has drastically changed cancer care delivery strategies. Patients with locally advanced head and neck cancer (LA-HNC) may be particularly affected by the COVID-19 pandemic, as they often undergo treatments that require daily clinic visits (e.g., radiation therapy). The goal of this study was to characterize the lived experience of LA-HNC patients and their healthcare providers during the COVID-19 pandemic.

Methods LA-HNC patients who completed a full course of chemotherapy and radiation therapy during the COVID19 pandemic (N=20) and LA-HNC healthcare providers (N=13) participated in semi-structured interviews. Interviews were audio-recorded, transcribed verbatim, and analyzed for qualitative themes.

Results The COVID-19 pandemic had a significant impact on patients' overall quality of life and health care. Results were organized in four main themes: (1) increased psychological distress; (2) exacerbated social isolation; (3) added stress in clinic for patients and providers; and (4) delays in health care.

Conclusions Findings highlight myriad ways LA-HNC patients and providers have been affected by the COVID-19 pandemic. Results can inform the development of supportive interventions to assist LA-HNC in managing COVID-19-related stress and unmet needs related to social isolation and in-clinic support.

Keywords Head and neck neoplasms · COVID-19 · Psycho-oncology · Qualitative research · Quality of life

Introduction

Since March 2020, the COVID-19 pandemic has drastically disrupted various aspects of cancer care delivery and created ongoing challenges for cancer patients and providers [1]. Mandatory lockdowns and fears of contracting COVID-19 have resulted in delays in cancer care and routine screenings for many patients. As a result, it is estimated that the number

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of excess cancer-related deaths over the next decade will be significant [2]. Moreover, cancer patients are particularly susceptible to COVID-19 infection due to the immunocompromising nature of cancer and its treatments. For patients undergoing cancer treatment during the pandemic, this vulnerability is exacerbated by more frequent clinic visits during which patients are at increased risk of encountering infected individuals [3].

For head and neck cancer (HNC) patients, cancer care disruptions and COVID-19 risk may be particularly substantial [4, 5], as this population faces unique challenges even in non-COVID conditions. For example, treatment disruptions may lead to worse locoregional control and survival [6, 7], and procedures that are considered a routine part of HNC evaluation, such as endoscopic evaluation of the nasal and mucosal pathways, are considered high-risk procedures for COVID-19 exposure [8]. Consensus practice guidelines and prioritization tools for HNC patients were developed in response to the pandemic [9–11]. Nevertheless, patients receiving active treatment were required to navigate COVID-19-related disruptions and care changes. For many, this included daily clinic visits for treatments (e.g., radiation therapy) during broad policy changes to mitigate the risk of COVID-19 infection (e.g., social distancing requirements, inability to bring a caregiver to clinic appointments, frequent COVID tests). Yet, there is limited understanding of how the COVID-19 pandemic broadly affected the experiences of HNC patients on active treatment nor the experiences of their cancer care providers.

To address this gap in knowledge, the purpose of this qualitative study was to describe the lived experiences of patients with locally advanced (LA)-HNC who completed treatment at a free-standing NCI-designated comprehensive cancer center during the COVID-19 pandemic. In addition, this study sought to understand the experiences of HNC healthcare providers regarding how the COVID-19 pandemic affected their ability to provide care for LA-HNC patients and their perceptions of the impact of the pandemic on patients' experiences. Findings reported here were a part of a larger study aiming to gather feedback from HNC patients and providers regarding considerations and preferences for developing behavioral supportive care interventions for HNC patients. A better understanding of HNC patients' and providers' lived experiences during COVID-19 may be used to inform infrastructure improvements during the ongoing pandemic to help future patients navigate their cancer care.

Patients and methods

Participants

Eligible patients were (1) at least 18 years old; (2) diagnosed with LA-HNC; (3) finished cancer treatment within the past year including a full course of chemotherapy (i.e., minimum of 3 weekly doses or 1 bolus dose of cisplatin) and radiation therapy (i.e., minimum 6 weeks of radiation); (4) expected to survive at least 3 months; (5) able to speak and read English; and (6) able to provide informed consent. Patients with documented or observable psychiatric or neurological disorders that could interfere with study participation were excluded (e.g., dementia, active psychosis). Eligible providers were healthcare professionals who provide clinical care to patients with LA-HNC (e.g., medical oncologists, advanced practice providers, nurses). Medical students, fellows, and trainees were excluded.

Procedures

This study was reviewed by the Advarra Institutional Review Board and deemed exempt from oversight due to minimal risk (Pro00045231). From September 2020 to January 2021, a trained study coordinator worked with medical oncologists in Moffitt Cancer Center's Head and Neck Clinic to identify eligible LA-HNC patients using purposeful sampling. Eligible patients were identified by a HNC medical oncologist (KK) and approached by trained study coordinators (CB, KS) to assess interest in participating. After providing verbal informed consent, patients participated in individual interviews via telephone or zoom that were audio-recorded and averaged 75 min in length. Patients also self-reported their demographic and clinical characteristics via an online survey using REDCap, and clinical data were confirmed via electronic medical record review. Patients received a \$50 gift card for participating. In this same timeframe, providers in Moffitt Cancer Center's Head and Neck Clinic were recruited through referrals from medical oncologists and approached by one of the study Principal Investigators (LO) to assess interest in participating. After providing verbal informed consent, providers participated in individual interviews via telephone or zoom that were audio-recorded and averaged 38 min in length. Providers also self-reported their demographic characteristics and credentials via an online survey using REDCap. Providers were not compensated. LA-HNC patients and providers were recruited and interviewed continuously until thematic saturation was reached, which was continuously evaluated and considered adequate when no new themes emerged. Research shows that thematic saturation is typically reached within 12 individual interviews, and the most important elements of meta-themes become evident after as few as six interviews [12].

Semi-structured interviews were informed by an interpretive approach, aiming to understand patient and provider experiences, perspectives, and meaning-making processes. The semi-structured interview guides were developed by the study Principal Investigators (LO, KK) in collaboration with a qualitative specialist (BA) with multiple rounds of revisions. Guides included questions and exploratory probes about treatment experiences during the COVID-19 pandemic, which is the focus of this paper. Guides also included questions about treatment and recovery, psychosocial concerns and needs, and perspectives on developing behavioral interventions for HNC patients, which will be reported on in future publications. Patient interviews were conducted by trained study coordinators (CB, KS) who were unknown to participants. Coordinator training was led by a qualitative specialist (BA) and included conducting a pilot interview with one patient each (two pilot interviews total). Audio recordings of the pilot interviews were reviewed by the qualitative specialist, and feedback was provided to each interviewer before additional interviews were conducted. Pilot interviews were incorporated into the data set after assessing for value and quality. Provider interviews were conducted

by a study Principal Investigator (LO) who is a licensed psychologist with extensive interviewing experience and was unknown to participants.

Analyses

Patients' demographics and clinical characteristics as well as providers' demographics and credentials were characterized with descriptive statistics using SAS version 9.4 (Cary, NC). The audio-recorded semi-structured interviews were transcribed verbatim using NVivo's artificial intelligence (AI)-assisted transcription software. The analytical process was led by two experienced qualitative specialists (BA, CG), guided by applied thematic analyses [13], and involved four steps. First, the qualitative specialists read all interview transcripts to gain a broad understanding of the data while recording initial impressions. Next, they developed a deductive preliminary codebook of a priori codes and definitions. The codebook was refined through multiple rounds of reiterative coding to achieve acceptable intercoder reliability (Kappa = 0.80). Coding discrepancies were resolved by consensus. Then, the qualitative specialists conducted line-by-line coding of all interview data using NVivo 12 Plus software. Throughout the coding process, emergent codes and subcodes were inductively identified and integrated into NVivo for a second round of coding. Finally, findings were synthesized by categorizing coded data into primary themes and subthemes. COREQ qualitative reporting guidelines were used to inform comprehensive reporting [14].

Results

Participant characteristics

Interviews were conducted with 20 LA-HNC patients and 13 HNC providers. Table 1 shows patients' demographics and clinical characteristics as well as providers' demographics and credentials. On average, patients were 60.6 years old (SD = 9.0). Most patients were White (90%), and all were non-Hispanic (100%). The most common LA-HNC diagnosis represented in the sample was cancer of the oropharynx (70%) followed by cancer of the nasopharynx (15%). On average, patients had completed treatment for LA-HNC 5.6 months prior to their interview (SD = 4.0). Providers were medical doctors (54%), registered nurses (23%), advanced practice nurse practitioners (8%), registered dietitians (8%), and speech-language pathologists (8%). On average, providers had 9.23 years of experience working in oncology post-training (SD = 11.66).

Table 1 LA-HNC patients' demographics and clinical characteristics (N=20) and providers' demographics and credentials (N=13)

	Statistic
Patient characteristics	
Age; M (SD) range	60.6 (9.0) 35–79
Gender; <i>n</i> (%)	
Female	5 (25)
Male	15 (75)
Race; <i>n</i> (%)	
White	18 (90)
Black or African American	2 (10)
Ethnicity; n (%)	
Non-Hispanic	20 (100)
Hispanic	0 (-)
Married; n (%)	
Currently married	13 (65)
Never married	2 (10)
Divorced	5 (25)
Education; <i>n</i> (%)	
College graduate	11 (55)
Did not graduate from college	9 (45)
Employment status; n (%)	
Employed full-time	9 (45)
Not employed full-time	11 (55)
Annual household income; n (%)	
Less than \$19,999	3 (15)
\$20,000-\$ 39,999	3 (15)
\$40,000-\$59,999	1 (5)
\$60,000-\$100,000	4 (20)
Greater than \$100,000	7 (35)
Prefer not to answer	2 (10)
CCI total; M (SD) range	2.3 (0.7) 2-4
Diagnosis; n (%)	
Oropharynx	14 (70)
Nasopharynx	3 (15)
Oral cavity	1 (5)
Supraglottic larynx	1 (5)
Ethmoid sinus tumor	1 (5)
HPV Status; n (%)	
Positive	14 (70)
Negative	4 (20)
Unknown	2 (10)
Months since diagnosis; mean (SD) range	9.1 (8.7) 3-17
Months since radiation; mean (SD) range	5.6 (4.0) .59–14
Provider characteristics	
Gender; <i>n</i> (%)	
Female	8 (62)
Male	5 (38)
Ethnicity; n (%)	· ·
Non-Hispanic	11 (85)
Hispanic	2 (15)

Table 1 (continued)

	Statistic
Race; <i>n</i> (%)	
White	6 (46)
Black or African American	1 (8)
Asian	4 (31)
More than one race	2 (15)
Highest degree; n (%)	
Doctor of medicine (MD)	7 (54)
Advanced practice nurse practitioner (APRN)	1 (8)
Registered nurse (RN)	3 (23)
Registered dietitian (RD)	1 (8)
MS in speech-language pathology	1 (8)
Years since highest degree; M (SD) range	12.31 (10.91) 1–38

CCI, Charlson Comorbidity Index; *HPV*, human papillomavirus; percentages may not add to 100 due to rounding

Qualitative themes

Four overarching themes emerged related to the experiences of LA-HNC patients and providers during the COVID-19 pandemic: (1) increased psychological distress; (2) exacerbated social isolation; (3) added stress in clinic for patients and providers; and (4) delays in health care. In addition to the quotes below, Table 2 shows other representative quotes for each theme.

Increased psychological distress

Patients frequently described COVID-19 as having a tremendous negative impact on their overall psychological state. Many patients described how their weakened immune system due to cancer and cancer treatment put them at a higher risk of severe illness. Thus, it was common for patients to describe worrying about contracting COVID-19, as exemplified by the patient quote below:

It contributes to a little bit of anxiety because, you hear over and over and over, people that are in a higher risk category. And, you know, by you being diagnosed with cancer, you're definitely put to the top of that list. So, it's very worrisome. 'Are you going to get COVID while you're getting treatment? ...What is that gonna do to your body? Are you even going to be able to deal with that? Are there medicines that are going to help you through that?' Just a lot of questions in your mind. (PT008)

Patients described being very aware of COVID-19-related risks and how to avoid exposure, such as avoiding crowds and close contact with others, wearing masks, and washing hands. Patients reported being more cautious about COVID-19 risk mitigating behaviors than the general community due to the understanding of being at higher risk of severe illness. One patient described this common fear:

Well, I'm afraid to go places. I'm afraid that if I catch the virus, it's going to kill me for sure because...I'm a person that has asthma, I'm over 65, so I had a couple of strikes against me already. And then with the cancer diagnosis, that's just, you know, it's game over. I don't want to catch a virus that's going to kill me. I feel like I got a lot of life left to live. And, you know, if it just means altering the things that we do and staying in. I mean, our most favorite thing in the world was going out to eat. We have not gone out to eat since COVID. (PT003)

Exacerbated social isolation

Patients most often referenced social isolation as one of the most challenging aspects of their cancer experience. Providers echoed the concerns about patients' social isolation. Importantly, providers described how acute and long-term side effects of LA-HNC treatment that affect the ability to eat (i.e., dry mouth, difficulty swallowing, mouth sores) can be socially isolating and can negatively impact patients' quality of life even outside the context of the COVID-19 pandemic. For example, one provider stated:

One of the less obvious symptoms would be social isolation...let's just say it's Thanksgiving time...they're not going to be able to eat typical foods with other people...so that adds a social component to this as well, unfortunately. (PV512)

Patients and providers described how social isolation has been exacerbated by the COVID-19 pandemic, with patients identifying significant reductions in social support during treatment. One patient emphasized how being alone has likely made their recovery more difficult:

Because of COVID, I was by myself over there... if I would have had that support, I may have eaten better; for someone to be there to push me to drink a Boost or you're going to make [food] for me. Because I had to get up and make it myself, which was tiresome in and of itself. But, you know, I got to say a few times I said, 'Gee, I wish my mother would fix me breakfast' or something like that... and you'd sit there in bed and think, 'I got to get up and eat. I got to get up and eat.' But, you know, an hour later, you still find yourself sitting in bed and you still haven't eaten. (PT013)

Table 2 Representative quotes from LA-HNC patients (PT) and providers (PV) organized by qualitative theme

Theme 1: Increased Psychological Distress

- "COVID is stressful to everybody right now... I think that we're worried about lots of stuff and, you know, throw the cancer in on top of it, it's like a double whammy." (PT011)
- "I'm more careful when I do go out. I wear a mask...I always consider myself clean, but I take it to another level; I come in and I take a shower for just going out to a grocery store. I don't know if it's a phobia...I guess that's the best way I can describe it." (PT015)
- "I think a lot of [patients] are just very anxious... because they're receiving chemotherapy and they're potentially immunocompromised." (PV501)

Theme 2: Exacerbated Social Isolation

- "I would say the that the pandemic has had at least as much to do with its effect on my personal relationships as my cancer treatment has because I was told very early on to pretty much just sequester myself because of the radiation and chemotherapy treatment. Any exposure to COVID-19 would be extraordinarily difficult for me to survive... So, it's had an obviously large effect on all my relationships." (PT001)
- "I was scared my resistance [to COVID-19] was low, so I didn't go anywhere... I didn't even go to the grocery store because I was worried about getting sicker. So, for a couple of months, I don't want to say I didn't have a life, but I didn't do anything but what I had to around the house. That was it." (PT020)
- "I also have another illness that I've had for 33 years, which is an immunity disease. My immune system is very low, so having cancer along with that, we've been isolating ourselves since March, my wife and I. And so we haven't seen anybody except a doctor, the grocery store, or gas station for 8 to 7 months now, I guess. It's been very, very confined. We do have social things on Zoom and other medias that we frequent. But of course, it's not the same as being with someone physically." (PT006)

Theme 3: Added Stress in Clinic for Patients and Providers

- "I really don't like the fact that when I go to a hospital, even Moffitt, my wife can't come in now. You know, she was with me through the whole thing...She's my sounding board when I'm asking questions. So that made it harder." (002)
- "Some [patients] are angry because Moffitt won't let their loved one in... What they're thinking about is what's going on in their world right now and they want that person. It's important for that person to be there with them and they can't... Let's say you're having a PET scan done to see if your if your cancer is gone and you don't have anybody there to celebrate with when you get a good report and you don't have anybody to cry with when you get a bad report. I just I can't imagine doing that all myself." (PV502)
- "I think one of the hardest things is when we could not have visitors come to our outpatient appointments... That was tough on everybody. That was tough from a clinician standpoint, making sure that the patient thoroughly was educated and understood the information we were giving them. And I think it was very hard on the patients because they rely on that social support and their family to be there at their appointments." (PV513)

Theme 4: Delays in Health Care

- "What has ended up happening is that a lot of patients have put a lot of their cancer care sort of on the back burner and have waited a long time to seek cancer care because they were just very afraid of COVID. That's something that we've seen a lot lately." (PV501)
- "When I first heard COVID on the increase, I missed y'all's doctor's appointment. I don't want to go nowhere. I didn't want to take the risk. And then, of course, I came over and saw you like a month later." (PT014)
- "Well, I'm due a colonoscopy this year and they said they weren't handing out any appointments until after COVID calmed down. So, I'm still waiting for that appointment." (PT011)

Another patient mentioned he felt worried about people visiting due to the pandemic. Despite the offered support, he felt isolated:

This just leads to isolation, that's all. And again, if this is a different time frame with no COVID, it would be different...Number one, I didn't want anybody coming over. Number two, I can't eat, you know? They're like, 'Well, what do you like to eat? We'll make you food.' I said, 'You're great and I love you guys, but you're not understanding. I can't even swallow liquid right now. That's how bad the sores are.' So, I think they begin to understand that. So, it's just the isolation. And again, I think I'm an outlier because it is, I have cancer during COVID. So that's...kind of a special category. (PT011)

Added stress in clinic for patients and providers

Patients described appreciating COVID-19 safety protocols in clinic. However, they also reported being negatively affected by the inability to have a caregiver or visitor (e.g., family member) accompany them during treatment and appointments due to visitor policy restrictions. Patients described how the inability to bring support was emotionally challenging and added to difficulties in obtaining and retaining information during clinic visits. For example, one patient described how he missed having his wife there to ask questions during visits; another reflected on more emotional aspects of being alone, as described below:

Not having my husband at the appointments because he comes, well, he used to come to every appointment that I took at Moffitt. So, him not being there, especially on those days when I was kind of nervous. Just like, when I had to do my scans; my first scans three months ago. And then, just dealing with like, not so pleasant news, but you're by yourself. I think that's been the most challenging part. (PT005)

Changes to visitor policies due to COVID-19 were also understood by providers as one of the most challenging aspects of providing care during the pandemic. Despite the ability to involve caregivers by phone or videoconference, providers described the additional time and effort needed to ensure patients retain clinical information during visits when they are unaccompanied. Providers described how this change added stress for patients, as well as providers themselves, as described below:

It adds an extra layer onto what is already a stressful thing for the patient... A lot of them feel a little bit more alone, and just kind of enhances what they're feeling and their anxieties. And then, they're not able to focus on what we're telling them, some of the education and things like that... I found that I've had to repeat myself a little bit more on education things, or what types of things that we're wanting patients to do, just because they don't have that extra set of ears or that support system... You're having to give a lot more support to the patients, which you don't mind, but it just kind of drains you a little bit more than you're probably used to. So, you kind of take it home with you a little bit more (PV504)

Delays in health care

While most patients described continuing to prioritize cancer treatment despite fears of contracting COVID-19, some patients discussed how the COVID-19 pandemic resulted in a delay in initial cancer visits as well as missed follow-up appointments. One provider described that it was common for patients to put their cancer care on the "back burner" due to fear of contracting COVID-19. This is further demonstrated by one patient's story about their experience of being diagnosed:

I wanted to see if [the swelling] would go down on its own, because I do tend to get swollen glands when I'm fighting any kind of illness. So, it didn't go down and then that's when...COVID hit. And so, I talked to a couple of friends of mine that are doctors, actually, and they're like, 'You know, I wouldn't do any elective procedure right now,' because COVID was starting to get really bad. And they said, 'You don't want to go to hospital for anything elective.' So, I kind of waited a little bit, but then it never went down. (PT011) Patients also reported delaying elective care or appointments viewed as "unnecessary," such as routine visits with dentists, chiropractors, and/or general practitioners. For example, one participant described how their concern of contracting COVID-19 informed their decisions in prioritizing care for their overall health:

I really haven't been to my primary care. I did one... tele-video thing, but I haven't had my annual physical and I haven't been to my dentist in 2020. So, [COVID-19] changed that. (PT015)

Discussion

To the best of our knowledge, this was the first study to describe the lived experience of LA-HNC patients and providers during the COVID-19 pandemic. A key finding was that LA-HNC patients had increased psychological distress while undergoing treatment in the context of a global COVID-19 pandemic due to worries about being at high risk for contracting COVID-19 and pandemic-related disruptions to cancer care delivery. This finding is notable, as HNC patients have disproportionately high rates of mental illness including depression and substance abuse/dependence [15–17], and rates of self-harm and suicide attempts are three times higher among HNC patients than the general US population [18]. Thus, routinely screening LA-HNC patients for distress and providing referrals to supportive resources are critical, particularly during the COVID-19 pandemic.

In addition to psychological distress more globally, COVID-19 exacerbated social isolation among LA-HNC patients. Social isolation is common during treatment for LA-HNC and is particularly affected by treatment side effects that affect social behaviors such as gathering to eat with friends and family [17]. Findings from this study support the conclusion that this social isolation was made worse by COVID-19 risk mitigation behaviors.

Relatedly, patients and providers described the negative consequences of being unable to have support persons accompany LA-HNC patients to clinic visits due to COVID-19 risk mitigation policies implemented in the cancer center. Per our interviews, policies restricting visitors in clinic, while required to reduce transmission risk, led to increased emotional burden for patients and providers. Patients lamented the lack of in-clinic support from close family and friends, while providers noted patients were often distracted due to clinic changes resulting in difficulty focusing on information providers were offering regarding their treatment and symptom management. The sudden onset of the pandemic brought forth a new set of challenges in implementing telehealth in clinics for patients, their caregivers, and clinic providers during the clinic visits. While telehealth technologies and other nontraditional care delivery strategies attempted to address these concerns by engaging caregivers via phone or video conferencing [19], our findings demonstrate that negative consequences persisted. Overtime, as there is more familiarity with telehealth platforms, care delivery will likely improve. However, until policies restricting visitors in clinic and similar restrictions are lifted, providers may have to use additional strategies to ensure patients are understanding important information they are given regarding their disease and treatment. For example, use of methods such as the teach-back technique or accessing pertinent materials via patient portals could help to confirm comprehension of complex messages and improve subsequent symptom self-management [20].

Notably, our findings show that a subset of patients delayed their LA-HNC care. Although it cannot be confirmed in our sample, it is possible that some patients may have ultimately presented to their oncologists with more advanced disease than if care was sought when symptoms were first noticed. While data regarding the so-called upstaging from delays to HNC care during the COVID-19 pandemic have not been assessed longitudinally, there is evidence of this trend in other cancer types [21]. Thus, as the COVID-19 pandemic continues, encouraging patients and the public to avoid delaying cancer care will be critical to ensure that patients receive care promptly.

The challenges related to the COVID-19 pandemic have been qualitatively explored in other cancer populations that compliment this study. For example, one study focusing on advanced lung cancer patients also found that the COVID-19 pandemic increased feelings of fear and anxiety, contributed to enhanced social isolation, and negatively affected the clinic experience (e.g., no visitors) [22]. Another study focused on the perspectives of breast cancer patients similarly found that COVID-19 increased general psychological distress, distress of experiencing cancer treatment alone, and social isolation [23]. This study extends the literature related to this topic by focusing on the experiences of LA-HNC patients and providers.

Study limitations.

This study was small and exploratory. In addition, the small sample of LA-HNC patients was mostly male, non-Hispanic White, and receiving care at an NCI-designated comprehensive cancer center. Thus, themes may not generalize to all LA-HNC patients who received care in community and academic medical settings. Future work should explore how COVID-19 affected the experiences of other diverse samples of LA-HNC patients.

Conclusion

To our knowledge, this represents the first qualitative analysis of the experiences of LA-HNC patients and providers during the COVID-19 pandemic. Results suggest that the COVID-19 pandemic worsened distress related to cancer care, exacerbated social isolation during LA-HNC treatment, created additional care challenges for HNC providers, and for some may have delayed cancer care. Future work should evaluate the long-term consequences of the COVID-19 pandemic on the psychosocial experiences of LA-HNC patients. Moreover, these results may inform the development of improved infrastructure during the ongoing COVID-19 pandemic to help future patients better navigate their cancer care.

Supplementary Information The online version contains supplementary material available at https://doi.org/10.1007/s00520-021-06773-x.

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Author contribution All the authors contributed equally to the manuscript.

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Data availability Not applicable.

Code availability Not Applicable.

Declarations

Ethics approval The current research was approved by the Institutional Review Board at Advarra (Pro00045231).

Consent to participate All participants provided verbal consent prior to study enrollment.

Consent for publication Participants provided verbal consent to have de-identified data published.

Conflict of interest Christine Chung—honoraria from Sanofi and Exelexis for ad hoc Scientific Advisory Board participation. Brian Gonzalez—paid consultant for SureMed Compliance and KemPharm outside this work and advisor for Elly Health outside this work. Heather Jim—paid consultant for RedBill BioPharma, Janssen Scientific Affairs, and Merck outside this work. Kedar Kirtane—owns stock in Veru, Oncternal Therapeutics, and Seattle Genetics. The authors have no other relevant conflicts of interest to disclose.

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