

The Enduring Effects of COVID for Cancer Care: Learning from Real-Life Clinical Practice



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ABSTRACT

For three years, COVID-19 has circulated among our communities and around the world, fundamentally changing social interactions, health care systems, and service delivery. For people living with (and receiving treatment for) cancer, pandemic conditions presented significant additional hurdles in an already unstable and shifting environment, including disrupted personal contact with care providers, interrupted access to clinical trials, distanced therapeutic encounters, multiple immune vulnerabilities, and new forms of financial precarity. In a 2020 perspective in this journal, we examined how COVID-19 was reshaping cancer care in the early

stages of the pandemic and how these changes might endure into the future. Three years later, and in light of a series of interviews with patients and their caregivers from the United States and Australia conducted during the pandemic, we return to consider the potential legacy effects of the pandemic on cancer care. While some challenges to care provision and survivorship were unforeseen, others accentuated and amplified existing problems experienced by patients, caregivers, and health care providers. Both are likely to have enduring effects in the “post-pandemic” world, raising the importance of focusing on lessons that can be learned for the future.

Introduction

Over the last three years, COVID-19 and the evolving societal responses to this viral threat have fundamentally altered almost every dimension of everyday life. Oncology practice and experiences of cancer survivorship have similarly been reconfigured as cancer care has adapted to the swiftly changing contexts of pandemic living, including evolving viral risks, the undulations of vaccine roll-outs and uptake, and ongoing public health measures such as lockdowns, distancing and masking. Our *Perspective* in this journal in 2020 took an early look at some of the structural fractures, emerging challenges and likely consequences provoked by the initial pandemic scene (1). Since then, we have seen how people living with cancer, and their families, have been disproportionately affected by the circulating and evolving virus, accessibility and safety of vaccines, and the implementation of public health measures to limit transmission. Various studies have demonstrated some of the many ways that COVID-19 has impacted cancer care and cancer survivorship, including impacts on accessing social supports (2–5), family participation in care (6–10), reassessments

of essential care (11–17), and dynamics of distance in clinical encounters (3, 18, 19). We now offer an updated analysis, based on patients’ and caregivers’ perspectives, as well as reflection on what the legacy effects may be in the future.

Background

Pandemic conditions changed almost all aspects of everyday life, and, while some elements appear to have returned to pre-pandemic norms, other changes endure. In the context of cancer care and survivorship, the literature hitherto provides some empirical context and consequences – practical and logistical problems – but thus far lacks a sophisticated understanding of the social consequences. That is, from a community perspective, what occurred and what are the consequences for the present and the future of survivorship? To foreground the community perspectives offered below, it is useful to review some of the social scientific literature and related concepts that may help make sense of the complex and swiftly evolving scene of cancer survivorship. These largely center around: the challenge of diminishing cultural attention to an issue of personal importance; derailing of the “shadow” supports that are often not in full view; and the dynamics of estrangement within the clinical context of distance. Such social issues come to center stage in community accounts of the complexities of pandemic life.

In terms of the first – a sense of systemic de-prioritization or fading cultural attention – this has been evidenced across many health and illness contexts [e.g., HIV/AIDS (20, 21), polio (22, 23), “neglected” tropical diseases (24, 25), and shifting global health priorities (26, 27)]. This speaks to the enduring social science concern around resilient health systems, which are able to accommodate “shocks”, without derailing support and community care practices. From a community perspective, major shocks can be experienced, as we explore further below, through the lens of neglect.

In terms of the second – the undulations of informal care – social science scholarship has routinely pointed to the interdependencies

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Translational Relevance

Since the early stages of the COVID-19 pandemic, there has been widespread interest in the ways in which this global health care crisis has affected already vulnerable populations. People living with cancer represent an important population who have experienced – and are continuing to experience – the changing and uncertain landscape of illness during a prolonged global pandemic. By centering real-life experiences drawn from interviews with patients and caregivers, we are documenting those experiences to create an evidence base on which to build more resilient care systems and increase preparedness for future pandemic (or other crisis) conditions. In the immediate future, it is important to understand how the pandemic has affected patients and their caregivers, to understand the potential legacy effects for patients undergoing cancer treatment and for cancer survivorship.

between formalized and informal sectors, both in cancer care and beyond [see, for example, literature on reliance on informal care and mixed-care networks (28), including family and non-kin caregivers (29) in the contexts of ill health (30) and/or aging (31)]. This work has also emphasized the opaqueness of reliance on informal caring networks, and what their role is in survivorship (32). The unintended consequences of pandemic conditions for (informal) networks of care emerges as a crucial lesson across both U.S. and Australian contexts.

In terms of relations of estrangement, the spatial dynamics of distance and proximity in the provision of care, including the micro-landscapes of the hospital room or clinic, the possibilities of remote/virtual care, and the significance of touch and separation have been key themes in health geography and related scholarship (33). Recent studies have interrogated how these dynamics were reconfigured in response to COVID-19 (34, 35), illuminating how the material environment shapes the quality and emotional resonance of care.

Design and Participants

This article draws on qualitative data from in-depth, semi-structured interviews with people living with cancer ($n = 65$) and their informal caregivers ($n = 28$), conducted in Australia from March 2020 to August 2021 and in the United States between February and July 2021. The interviews were carried out as part of a program of qualitative research focused on contemporary experiences of cancer care within the era of precision oncology. It involved a collaboration between health social scientists with experience in qualitative cancer research and clinician–researchers across four oncology services, aided and supported by five cancer-related consumer groups.

An interview discussion guide was developed for each of the contexts following a review of the conceptual and empirical literature, and with input from the diverse research team. The Australian interviews centered on therapeutic innovations in cancer care, whereas the U.S. interviews focused on experiences of cancer care in pandemic conditions. Interviews were semistructured and iteratively explored a range of issues around participants' lived experience of cancer and care. This included asking people living with cancer about their experience of diagnostics, treatment, care and (in some cases) recovery. Caregivers were asked about their experiences of their loved one's

diagnosis, treatment and care, and their experiences of supporting them through these experiences. This article draws specifically on an analysis of data relating to experiences of living with cancer during the COVID-19 pandemic in 2020 and 2021. Interviews were conducted remotely (via phone or video-conference), ranged from 17 to 127 minutes, were audio-recorded, and transcribed verbatim. Participants have been deidentified in this article to protect their anonymity. Institutional and ethics approval was gained through a metropolitan hospital on Australia's east coast (RBWH HREC EC00172, project no. 2019/50345) and the Institutional Review Board at Duke University (Protocol Pro00106262). Data were analyzed using the framework approach (36) and supported by NVivo V.11 qualitative data analysis software. Independent coding of the data was provided initially by L. Williams Veazey and A. Broom, who searched the transcripts for themes relating to the SARS-CoV-2 pandemic. This initial coding was then cross-checked by the broader research team to facilitate the development of themes, moving toward an overall interpretation of the data.

Pandemic and Health Services Contexts

Throughout 2020 and 2021, the U.S. and Australian contexts both involved widespread disruption to health services and the implementation of restrictions and mandates around physical distancing, the operation of businesses and public services, and protective measures such as masking. In both locations, such measures varied both across time (e.g., short-term lockdowns followed by periods of looser restrictions) and place, with local and regional governments taking differing approaches. The impact of pandemic-related disruptions on health care delivery also differed according to the various funding arrangements (e.g., centralized and state-level government funding, private health insurance, and so on). Within these diverse contexts, we undertook a program of research across Australia and the United States, which has asked those with cancer, and their caregivers, to put in their own words the impact of pandemic conditions on their care and survivorship experience. Most interviews were conducted prior to the widespread availability of COVID-19 vaccines in either Australia or the United States.

Findings

Beyond simply telehealth or face-to-face

As outlined in our original article, the “virtual pivot” at the start of the pandemic raised a wide range of challenges for both health professionals, patients and families. While this enabled both routine and nonroutine consultations to proceed, the advent of virtual consults has also created new forms of affective distance and unequal access (37–40). Initial concerns about the digital turn for equity of access and efficacy of clinical interactions were widespread, and data has since emerged to support these initial concerns, including of the fallout from care of those most vulnerable (i.e., with limited access to telehealth); those less able to utilize eHealth services (i.e., elderly, rural, or poorer); and the reduction in capacity for “difficult conversations” (i.e., prognosis/poor treatment outcomes and end-of-life discussions). Although these demographic and interactive consequences existed, our participants often focused on the appropriateness and facilities, rather than the online versus face-to-face dynamic per se. As shown in **Table 1**, this included such things as facilities for spouses and support persons to be involved, privacy, and targeted telehealth for routine conversations, not critical moments (i.e., treatment failure, prognostic elaborations).

Table 1. Indicative quotes: beyond simply telehealth or face-to-face.

Participant	Indicative quote
Patient, F 50–70, neuroendocrine cancer, Australia	It's just a disembodied voice on the phone who's telling you whatever news about your scan. . . I just felt it was unsatisfactory because I couldn't ask him questions about my results. He always gives me my results, the printouts of all the scan results and things and the bloods all come to me. But this time, our two-minute call was over and then the nurse emailed my results to me. But you can't actually ask him about anything on those results or clarify anything. You can't discuss anything else with him because it's all over and done very quickly.
Patient, M 50–70, neuroendocrine cancer, Australia	And I actually emailed him all my questions beforehand, which I think was a really good thing to do. And then I recorded him, with his permission, on the speaker phone. I probably would have preferred a Zoom, but he does telephone things now.
Patient, F 51–70, ovarian cancer, United States	I think, if I am feeling well and everything seems to be going well, I'd rather do it telehealth. When I was having problems with my port area, I definitely wanted to be there in-person, because they had to see- I mean, I sent pictures for people to evaluate, etc., but to be there in person to actually have them see it is it is a big difference.
Husband, M 51–70, neuroendocrine cancer, Australia	Well, I just think she'd feel more comfortable being face-to-face. If the doctor needs to examine her, she can examine her or he can examine her or whatever. We can't do that through a video. They can't reach out and get someone's pulse and listen to their heartbeat. It's a little bit hard.
Friend, F 51–70, neuroendocrine cancer, Australia	I just think for a medical appointment, I just feel like you need a bit more reassurance perhaps. A little bit more of that closeness, I think.
Patient, M 30–50, pancreatic cancer, Australia	It wasn't even Zoom: Zoom wasn't offered. It was just telehealth. Actually, sitting down and reading their eyes and letting their eyes read you, I miss that. Whereas you're just on the phone, like now, and someone's just reading a report and saying, "How are you going and everything?" when they can't actually see you or you can't actually show them where you're having the stomach pain, et cetera, that sort of stuff. So that's what I miss. So, I personally wouldn't mind a combination of both, up to the patient, so as well as to say, "I'm sort of busy that week. I'd prefer telehealth." But normally I'd prefer a face-to-face.
Husband, M 30–50, neuroendocrine cancer, Australia	Telehealth, the hospital's not very good at telehealth. Maybe it's the staff, maybe it's the tools they have, but they seem to struggle with it. So yeah. I mean, it's good because we don't have to go in. . . So it's cut down on our travel time and the impact it has on us as far as just getting in there, which is good. And there's a lot of appointments that have never really needed to be face-to-face. So, in that regard, to be honest, it's better. But they're not great at actually establishing a Zoom call where you can actually see their face. [. . .] They can barely get their face on the thing, let alone be able to actually show you images. So, they're just not set up well for that sort of thing, and we'd just rather be there and see it and be able to ask questions.
Patient, F 30–50, lung cancer, Australia (c)	For me, that takes away the driving to the hospital or the arranging childcare-type thing. And, I mean, the last phone call I got from the oncologist a week ago, I swear I was on that phone for one minute. [. . .] And the one before that was actually in person and I drove an hour-and-a-half, or my friend did, to get there. Waited 40 minutes-plus in the waiting room and saw him for five minutes.
Patient, F 51–70, breast cancer, United States (b)	I think it is something that the physicians should say, "this is something that we are going to do for our patients" by having a small video-conference room on the premises where the spouse or support person can sit comfortably, and in private, and do the video consultation with patients and the physician, if the support person is not allowed in there. Not in a public waiting area. Not outside the building. Not in your car. Not in a restaurant down the road. A physician should not also be assuming that, well her spouse is going to be sitting at home, looking at the computer at home. The support person/spouse can't be driving the patient to their appointment and get back home in time to sit at the computer at home.

The impact of pandemic living on networks of care

Alongside virtual consults, in-person appointments continued for many people to enable essential treatment and care. When writing our original article, we did not anticipate, or consider, the exclusion of informal caregivers, friends, and family from these in-person appointments, and the impact that would have on survivorship and capacity to cope. Such restrictions on supporters or visitors were widespread across contexts, although the details varied (41). As shown in **Table 2** below, for the participants in our studies in Australia and the United States, attending appointments alone increased the emotional burden on the patient (patients were "petrified" and "lonely") and made the appointments less effective for conveying important information as patients noted they were too "overwhelmed" to absorb information or ask important questions. This, of course, speaks to enduring concerns around the (often undervalued) practical and emotional caregiving performed by friends and families of people living with cancer (31, 42, 43). Caregivers themselves felt powerless to

help from outside the hospital and, furthermore, health professionals carried an increased emotional load when discussing care and difficult prognoses without anyone to provide the necessary emotional support to the patient.

Mutual vulnerability and clinical estrangement

During the first two years of the COVID-19 pandemic, and particularly prior to the development of vaccines, health care environments became places associated with elevated risk and fear (e.g., of infection) for clinicians as well as patients (44). Changes and restrictions in the hospital aimed at increasing safety for patients and clinicians by ensuring physical distancing included the introduction of PPE, changes to the physical environment and to routines of care (34), and the exclusion of visitors (as noted above). These physical and logistical changes, put in place to guard against the mutual vulnerability of patients and clinicians, also produced estrangement. The barriers to communication introduced by the wearing of masks

Table 2. Indicative quotes: the impact of pandemic life on networks of care.

Participant	Indicative quote
Patient, F 51–70, bladder cancer, United States	My husband had to drop me off at the door and I had never—This was a huge building and I was having surgery that day. I was petrified. I was terrified. And I'm a nurse, you know. And to find my way – we didn't even know if I was in the right building. My husband didn't know either. It looked like it was the right building. I got in. It was very easy to get lost. I was in tears. [...] Except for the day that I found out I had cancer that was probably my second worst day of this cancer – was trying to find my way around. [...] I mean, I'm an astute woman. I can find my way around places but when you are already fasting, I know I'm looking at surgery in the next couple of hours, at a new place, I knew I was getting chemo that day- it just kind of overwhelmed me.
Patient, F 30–50, lung cancer, Australia (a)	And it was really horrible going to the appointment. You couldn't take a support person with you. . . . And to sit there and get that news, that it had doubled in size in the six months since my brain scan before, and I walked out of there and there were so many questions that I asked, but I don't remember the answer. Like, "When should I have my follow-up scan?" and things like that. Because normally, if you have somebody with you you've got two [sets of] ears listening, so when you walk out you kind of go, "Okay, well I need to book this in and do this and do that." But because it was myself and I was a bit overwhelmed, it's not very often I go by myself, and so it just reinforced the importance of having someone there. And the consequences of that have been quite dramatic.
Patient, M 51–70, prostate cancer, United States	But, you know, she was able to go with me to the first meeting at [cancer hospital], and the rest of the time she was kept out in the cold and the snow- and wasn't able to actively participate. I rely on her for my medical information, so it made it very stressful. Very stressful.
Wife, F 51–70, prostate cancer, United States	[He] came out of those appointments that he went to by himself – when I asked him what they said – he couldn't tell me and that he didn't know what questions to ask. His appointments were brief. He has a PhD in chemistry and graduated from MIT. He had no understanding, or very little understanding, of what was going on because he went by himself and he was so overwhelmed. . . . Every time we went, we asked for help. We said, "Is there a social worker we could talk to?" No one available. "Is there a family-patient relations department?" They were working from home, we couldn't talk to them. I asked if they had a clinical coordinator, they didn't know what that was. So when you asked the staff for help, they don't know what the resources are to help a family that's overwhelmed.
Patient, F 51–70, ovarian cancer, United States	So the care itself, you know, with the hospitals and everything, nothing of mine was delayed- but it was a lonely journey – and you felt more alone.
Patient, F 30–50, lung cancer, Australia (b)	I was there by myself, yeah. So, that was very, very raw. Yeah, very difficult. [...] I told [husband] when I went out to the car. He was waiting for me in the car. But I did ask my oncologist if she would talk to him as well, I think it was just so that he would understand it from a medical point of view rather than just coming from me because maybe I was emotional about it. I don't know. Yeah, I wasn't really sure. I just felt that it would be better for him to hear it from her rather than just from me. I can't really tell you why that is [...] I guess it was a way of him being there, yeah, being there with me.

and face shields, for example, are well documented (45–47), and this was clear from our patients' experiences too (see **Table 3**). In the heightened emotions of a cancer consultation, a clinician's perceived rejection of a patient's paper list of medications, or their decision to maintain distance, introduced an element of emotional vulnerability or unease to the clinical encounter. Conversely, where clinicians were seen not to "hold back" from patients, the sense of emotional support was increased. On the other hand, a perception of inadequate safety measures increased patients' sense of fear and lack of trust in the institution.

Disruption and uncertainty in accessing clinical care

Over the course of 2020–2022, cancer care professionals, as with many other providers, tussled with physical distance and intimate-clinical relationships in the context of changing norms, knowledge and requirements around PPE, vaccines and infection control. In particular, patients were conscious that their ability to access clinical trials and treatment were impacted by travel restrictions, a crisis in health care provision, and a prioritization of COVID-19 research. When vaccines were rolled-out, additional uncertainty emerged over the distribution of vaccines and in the lack of specific guidelines for those with various cancer treatment regimens (**Table 4**). With cancer representing an emotional journey for patients and families, the vulnerability of all parties within the pandemic-care journey moved to center stage, both in terms of the significance of proximity (repre-

senting care), and the estrangement of protection (undermining a sense of care; **Table 4**). Seen across many contexts and continents, the uncertainty layered over uncertainty, created a fraught environment, which spoke also to the difficulty in knowing what information to trust and prioritize in a volatile environment:

Competing priorities and the diminished social attention to cancer

A paradox evident in the context of having cancer and living within a pandemic, is the competing priorities that it represents (to both patients, families and societies). For some patients, this induced a sense that cancer was disappearing from cultural attention, as well as the attention of clinical trials. That is, diminishing attention works in multiple directions concurrently, both offering a sense of withdrawal of community support and momentum for cancer survivorship, and in turn, distracting stakeholders (including health professionals) from the focus of person-in-care. For others, there was the belief that cancer helped diminish some of the anxieties about the pandemic and its significance. These tensions are clear in **Table 5**. Cancer in the pandemic also shaped the way family life could be experienced, as patients were impacted by their family's struggles with lockdowns, while also confronting that the pandemic may have foreclosed particular opportunities for "bucket lists" and the celebration of remaining life with family and friends. This was articulated as stolen time by patients and caregivers, as

Table 3. Mutual vulnerability and clinical estrangement.

Participant	Indicative quote
Patient, M, >70, head and neck cancer, United States	In fact, both doctors were telling me, “[X], you need a colonoscopy. I looked at them and said, “You’re kidding me, I’m not going to a hospital right now.” There’s no way to get me into a hospital. I have been in public places, nursing homes, as late as April and know a lot of medical professionals in our community and the head nurse of a 400-bed nursing home, who I’ve known for 20 years and knows me well- we see each other at least once a month. So she saw me in the building and she said, “[X], get out of here. I know your medical history. We have had too many deaths, you don’t need to be in this building.”
Patient, F 51–70, breast cancer, United States (b)	She said to me, when I told her I had my list [of medications] ready for her, “I don’t want that.” But patients are constantly told to bring a list of current meds to every appointment. Her demeanor upset me so much; I forgot everything she said to me during the appointment as far as my treatment. When I returned home, afterwards, I started sobbing. . . . Possibly, she was afraid of contact. I had my list printed on a sheet of paper to hand to her. If she had said, “I don’t want to hold that paper in my hand because of possible contact,” I would have understood that.
Patient, F 50–70, rectal cancer, United States	And like I said I don’t know that the pandemic plays into that because, you know, they probably don’t want to be too close to people, but at the same time, they still need a little bit more.
Patient, F 50–70, bladder cancer, United States	I think communication is a little more difficult with your face covered up with the mask. It’s hard for-sometimes we have to ask people to repeat things because it’s affected hearing and speech [. . .] I do get it. It just seems more cold.
Husband, M >70, neuroendocrine cancer, Australia	I suppose one of the things that happens is that each time we go to the hospital you get temperature tested and sanitized and whatever. . . . But it’s a little bit scary, in a way, because, I mean, normally when you walk into a hospital environment these days there’s usually a nice, open, airy space with heaps of people walking around, and suddenly you’ve got all these people in gowns and masks and asking you all these questions and taking your temperature when you’re not expecting anything sort of thing. It’s a change in perception or a change in what’s happening.
Patient, F 50–70, lung cancer, Australia (d)	There’s a crowded waiting room and I stood outside for a couple of hours in the car park because I just didn’t feel safe to go in there. And so I think I’ve become extremely risk averse and I’m probably socially physically isolating as much as I can.
Patient, F 50–70, neuroendocrine cancer, Australia	I was actually quite horrified when I walked into the waiting room there, that everyone was not distanced. The chairs were still in the waiting room exactly as they always are, in a big circle around the walls. The only concession was a bottle of hand sanitizer by the sign-on touch pad, where you enter your name when you come in, to do your hands. And you just sat where you always did. So I had to look for a little spot that wasn’t near everyone. And everyone coming in was doing the same, looking for somewhere not next to everybody else to try and keep distancing going. They had some little circles on the floor to stand where the receptionist is, and they’d put up some Perspex screens. And I thought it was very inadequate really.
Patient, F >70, breast cancer, United States	The people that did the radiology component. They were really good. They didn’t hold back. They weren’t like “don’t come close.” I mean like none of that, I didn’t experience any of that. In fact, they were running a program for students who were learning, who were placed by the university, it was there. . . .you know when they come and. . . it was their practical. They were wonderful. They didn’t stand back. They weren’t afraid. They weren’t worried. It was amazing. It was amazing.

noted in **Table 5** below, which in turn induced a sense of lost time, amidst shrinking worlds.

Going forward: the importance of in-depth analysis to understanding the legacy effects of the COVID-19 pandemic

In 2020 we asked: how can we best support patients, families, and one another in ways that foster adaptation and equity, rather than assuming an eventual return to prepandemic relations and linear effects across patient groups? Periods of crisis and rapid change can reveal what is important in various aspects of our lives, as well as our vulnerabilities, and the precarity of various systems. The reflections of patients and caregivers in this paper need to be recognized as a crucial insight into what holds meaning and value to those receiving cancer care, and their families. Disruption, uncertainty and mutual vulnerabilities were key themes in the experiences of patients and their caregivers as they navigated the unknown territory of cancer

treatment during a global pandemic. While the adoption of telehealth and adjustments to face-to-face healthcare helped enable some continuity of care provision in the context of heightened infection prevention concerns, our findings highlight the ways these measures worked to exclude families and other informal caregivers from the networks of care which sustain the patient through treatment and beyond. In a pandemic, negotiating the difficult dynamic between proximity/care and distance/protection is a central challenge in both the clinical encounter (between patient and health professional; ref. 34) and in these broader networks of care. These insights from patients and caregivers provide not only an evidence base, but key principles for rapid change were it to happen again (when it happens again). These perspectives also provide insight into the pandemic experiences which continue to shape the experience of cancer care, and the underlying/structural inequalities and vulnerabilities that remain in oncology practice despite the desire to return to an elusive “normal.”

Key insights	Recommendations for care providers
The COVID-19 pandemic elicited feelings of uncertainty, fear and vulnerability among patients and health professionals.	Institutional pandemic plans for the future should formally integrate lessons from social, emotional, and technological challenges evident during COVID.
On top of disruptions to their care, cancer patients had to cope with disruptions to informal support networks and diminished cultural attention to cancer.	Pandemic plans should include provision for increasing social support (e.g., access to social work professionals and/or means to facilitate informal care) and public communication strategies to acknowledge and counter the perception of a pull of attention away from patient circumstances.
Telehealth was more suitable for some types of appointments than others, and was not always done well.	Health systems should invest in technology and training to ensure telehealth provision is adequate to patient needs. Patients and care providers should discuss appropriateness of telehealth appointments on a case-by-case basis, with institutional guidelines for support.
Face-to-face appointments that excluded the support person (for infection control purposes) often left patients feeling scared and/or confused.	Care providers should facilitate remote participation of a support person where they are prevented from attending in person (e.g., set up a separate room with video connection).
Many patients were afraid to visit hospitals (due to fear of infection). Safety measures (e.g., PPE) built trust in care providers but also introduced emotional distance and communication difficulties.	Care providers should consider ways to overcome emotional distance (e.g., friendly signage, verbal reassurance) and communication difficulties (e.g., voice amplification, clear written materials).
Support systems for patients, families, and caregivers need constant adaptation to provide equitable and balanced access to care during usual but also extraordinary circumstances.	Preparedness for pandemics and other crises (e.g., natural disaster, terrorism...etc.) should be an integral part of health policy and strategy.

Table 4. Indicative quotes: disruption and uncertainty in accessing clinical care.

Participant	Indicative quote
Patient, F 51–70, sarcoma, United States	One of the strong recommendations for people with sarcoma is that you get seen at a high-volume center that does a lot of sarcoma treatment. And, because of COVID, I was not able to do that. . . [State]’s laws prohibited me from doing telemedicine with them, so I was stuck with my doctors talking to them and translating what they said to me as opposed to me being able to talk with them and ask them the kind of questions I would normally ask to get comfortable with whatever treatment that I am engaging in.
Patient, M 51–70, brain cancer, Australia	I was on the dendritic cell vaccine thing from 2015 to 2018, one injection a month. 2019, I had it every second month. [. . .] And then in 2020, because of COVID [and travel restrictions], I only got two injections. . . So, effectively, in 2020 the cancer’s come, I’m suggesting, I don’t know, cancer’s come back. It’s been detected in March ‘21. And obviously, from now, in March ‘21, well, we’re doing it every month.
Husband, M 30–50, rare cancer, Australia	We just said, “What about the trial?” and he goes, “They were all put on hold.” He said, “I went to them and they got put on hold.” I think 90% of trials just got stopped.
Patient, F 51–70, breast cancer, United States (a)	So, I mean, for us, we have to travel. So normally we would have flown down, like just catch a cheap Southwest flight. It’s only about an hour. But, (a) we didn’t want to be on anybody’s airplane for even an hour even with masks on, (b) the rental car, I don’t know how clean that is. . . it’s like 5 hours [to drive].
Patient, M >70, head and neck cancer, United States	I have it in writing, from both my doctors that I am not to take the vaccine. None of them at this point in time, which is of course putting somewhat of a crimp on my life. Reason being, we have contacted Pfizer. We’ve contacted Moderna. We’ve contacted Bristol-Myers Squibb and nobody can tell us if there will be any sort of interaction between the Optivo and any of the vaccines that are out there right now. We have no information whatsoever from the horse’s mouth. . . I would be willing to mask the rest of my life until somebody does a study somewhere that says, you know, with Optivo you can take one of the vaccines. . . But nobody knows and it’s scary when you talk to people at Pfizer and Moderna and they say, “we don’t know, we can’t tell you, there’s been no studies done.”
Patient, F 30–50, lung cancer, Australia	So, those people on the forum talked more. . . some of them came back with zero antibodies, some of them come back with some low number of antibodies. . . And so they started to get worried, and so I started to get worried. And so yesterday I had a follow-up with [oncologist] and I did ask him whether I can do a blood test to check my antibodies. He said, “None of that is available in Australia yet unfortunately.” He said that there’s possibly not enough evidence to say that that is okay. So he said, “Just take the precautions.”
Patient, F 51–70, breast cancer, United States (a)	I was trying everything to get the vaccine. And so how things have been rolled out is horrible. And I only got mine because my church partnered with the hospital and I knew the person running the health ministry. And I said, “Well if at the end of the clinic, it’s coming to the end of day you feel like there’s extra, let me know.” So we rushed and drove down and that is how we got our vaccine. Other than that, you know you are at risk and there is no way to get this vaccine. So communicating to patients proactively would be good because that caused me a lot of stress.

Table 5. Indicative quotes: competing priorities and the diminished social attention to cancer.

Participant	Indicative quote
Patient, F 51–70, endometrial cancer, United States (speaking about husband who was in cancer treatment in 2020)	I think, probably, one of the hardest things with my husband's journey was getting people to- well not necessarily getting people to realize, but people not realizing what he was going through because everybody was in, "Oh my gosh, the world is coming to an end. This is chaos" mode. And people not realizing that on top of everything everyone else is already experiencing, you know, he was going through his cancer journey at the same time. And people going, "Oh my gosh, this is horrible. I haven't been out to eat in three months." And I was like, well that's great, but that's not the end of the world.
Patient, F 30–50, lung cancer, Australia (a)	So, I actually was never worried about COVID, I'm still not, I'm really not, because, yeah, I don't think there's anything worse than being told what I've been told. You'll never know what it feels like to have that kind of life. So yeah, I take COVID seriously, but I don't see that as a priority in my life. I really don't want to live my life in fear, and I never will. It's just another thing that I'm trying to navigate, to be honest.
Patient, F 51–70, breast cancer, United States (a)	So, I've got to hand it to them, they don't want to put me at risk it's just that it has restricted them a lot. . . my youngest son, I feel the worst for him because he has lost a year and half of college and college life. You know, he came home in March of 20 and his summer internship was supposed to be in New York, on Wall Street. So he ended up doing it here at home, virtually, and that was 16 hours a day. So he didn't get that experience and now school is still online- because he is back in LA and so he's lost like a year and a half of college. . . Yeah and so he went back to LA- I can understand that- I wanted him to stay here but he went back to LA so he could at least be around, not really, but some people - you know, his roommates, his girlfriend. So you know, so at least he could feel a little better. . . His one roommate was a little reckless. He said he was on Instagram and saw that the roommate was out at frat parties and stuff- and he said, "Dude, I've got to go home to my mom, can, you know, tone it down for like a week or two?" And the guy said, "No." And so my son checked into the University Hotel.
Patient, F 30–50, lung cancer, Australia (a)	But for me personally, it took away another part of what I was really hoping to do, which was to travel, and to see my real world. And to get that sort of taken away, it felt really limiting to already what felt like a limited life. So, in one sense, yeah, I hate the fact that it's stopping me from doing what I really, really wanted to do. And I don't think people understand it on that level because you will get out of this, we will get out of this, but I will not be able to get out of what I have. That's my reality. . . I feel limited. I feel really, really, even more so, because I have such a limited time. I feel like it's limiting me.
Patient, F 51–70, lung cancer, Australia (b)	When you don't know how much time you've got, each day that you're stuck at home is taking another day away from making a really positive experience. So, yeah.
Patient, F 51–70, neuroendocrine cancer, Australia	Yeah, second wave has shut that down. Well, I was meant to be in Canada in April and I was meant to be in the snow at the end of this month, and now I'm not. So, I'm really worried about dying during COVID without ever having done anything else meaningful. <i>Interviewer: Can you elaborate on that for me? What do you mean by "meaningful"? What's going on there?</i> Well, sitting on the couch, watching TV, painting miniatures, doing puzzles, it's not really life. It's not like I'm sad about it, but, well yeah, in some ways I'm sad about it. I want to be out having adventures or doing fun things.
Son, M <30, lung cancer, Australia	So [my siblings] were initially getting married this year, but that got postponed due to the pandemic. But it was hard for them because they were not sure whether to try and bring things forward because they weren't sure how soon Mum will become unwell, and they want Mum to be well enough to enjoy the wedding and stuff like that.

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