

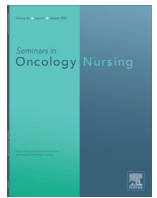
Exploring experiences among people diagnosed with cancer during the COVID-19 pandemic: a qualitative descriptive study.

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Exploring Experiences Among People Diagnosed With Cancer During the COVID-19 Pandemic: A Qualitative Descriptive Study

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ABSTRACT

Objectives: To describe the experiences of people diagnosed with cancer during the COVID-19 pandemic.

Data Sources: Qualitative data were collected through semistructured interviews conducted with people affected by cancer in the Australian context. Following institutional ethical approval, interviews were conducted over Microsoft Teams and Zoom platforms and complied with confidentiality requirements. Data were transcribed verbatim and analyzed, and emergent themes were developed using thematic analysis to understand patient experiences of cancer care during the COVID-19 pandemic.

Conclusions: The COVID-19 pandemic was disruptive to the daily experiences of supportive care. Four overarching themes were identified related to: 1) the impact on accessing healthcare services, 2) encounters with healthcare professionals, 3) the impact on daily living, and 4) the impact of COVID on psychological well-being.

Implications for Nursing Practice: As the COVID-19 pandemic held global consequences on cancer practices, it is recommended that nursing and other multidisciplinary healthcare professionals reflect upon these findings, in the context of planning for future pandemics. We encourage further exploration into the sustainability of telehealth services universally, given the issues highlighted in this study.

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Introduction

In March 2020, the World Health Organization (WHO) declared COVID-19 as a global pandemic. To date, there has been 760,360,956 confirmed cases and 6,873,477 deaths.¹ It is imperative for healthcare professionals and researchers to comprehensively understand the impacts of COVID-19 among people affected by cancer. A recent systematic review² identified the supportive care needs for people affected by cancer during the COVID-19 pandemic. The findings from this review² identified that irrespective of cancer type or stages and treatment or COVID-19 status, patients reported reduced access and availability for symptom management support during the pandemic. Many people affected by cancer expressed concerns related to increased fatigue, weakness, and pain during periods of increased distress and anxiety evoked by repetitive lockdowns and reduced accessibility to healthcare services.² Furthermore, individuals expressed fears

of contracting COVID-19, forcing them to socially isolate themselves from not only the wider community but also peers, family, and support networks. Communication with healthcare professionals decreased in quality when care was transitioned to telehealth services.^{3–20} While there are several issues in supportive care experiences among people affected by cancer during the pandemic, there are several limitations to point out in this existing systematic review.² First, while the review was inclusive of all global literature, there was little insight into the experiences of people affected by cancer within the Australian health system. Noteworthy, there was only one Australian study²¹ that was conducted in a population of adults with hematological cancers and was quantitative and cross-sectional in design. Consequently, little is known about the in-depth lived experiences of people affected by distinct types of cancer across both private and public Australian healthcare services. While Australia did not experience the same level of impact of the pandemic compared to other countries, Australia experienced harsh lockdowns, with longer periods of time compared to other countries.²² For example, Melbourne claimed the dubious title of being the world's most locked-down place after 246 days in lockdown.

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Cancer services still had to manage burgeoning clinical service demand due to COVID-19 and adapt to adhere to constant changes in legislation, restrictions, and transition cancer service models of care to models of telehealth.^{23,24} Currently, there is limited information about the experiences among people affected by cancer in this context, to inform future clinical service re-design and to learn and plan cancer services for future pandemics.

This qualitative study aimed to address the following research question:

What are the experiences among people diagnosed with cancer during the COVID-19 pandemic in Australia?

Methods

Design: A qualitative descriptive study method²⁵ was used to examine patient experiences of those living with cancer in Australia during the COVID-19 pandemic. This study design enabled a rich and in-depth exploration of qualitative experiences. Semistructured interviews²⁶ allowed for the depiction of an individual's experiences rather than a cohort response. We aimed to qualitatively synthesize the information shared by Australians living with cancer who were affected by COVID-19, to highlight their experiences. This study has been reported according to the Consolidated Criteria for Reporting Qualitative Studies (COREQ) 32-item checklist.²⁷ See [Supplementary Table 1](#) for the completed checklist.

Setting: Private and public cancer services across Australia were included. Seven of the eight participants lived in Australian Capital Territory and one participant resided in northern New South Wales. Interviews were conducted over Microsoft Teams or Zoom and dictated using the in-built tools, recorded, and transcribed for quality assurance purposes between September 2022 and February 2023.

Eligibility Criteria: Participants were selected based on meeting the following inclusion criteria:

- Participants diagnosed with cancer, irrespective of type, staging, or treatment services.
- Participants either had been diagnosed with COVID-19 or had been a close contact to someone diagnosed with COVID-19 in their household. The diagnosis of COVID-19 was self-reported.
- Participants who were ≥ 18 years or older and able to provide written and informed consent.
- Participants of all genders were included and were self-assessed proficient in English.

Recruitment

The snowballing approach²⁸ to sampling was used to capture patient experiences across Australia. This method aimed to encourage as many diverse participants as possible to take part in the study and, therefore, no participant was directly targeted based upon diagnosis, age, gender, or location. Participants were provided with a participant information sheet and provided with the opportunity to ask questions. All participants were assured that their comments would remain confidential, and that all data collected would be deidentified. Participants were recruited following national participant recruitment strategies:

- One researcher contacted, by email, sixteen known cancer organizations listed on Cancer Australia (<https://www.canceraustralia.gov.au/impacted-cancer/cancer-support-organisations>). The peak cancer organizations were provided with an overview of the study, a copy of the participant information sheet, and recruitment poster. The organizations were asked to advertise the

research study on their websites, and to share in their email distributions lists. In total, 6 of the 16 cancer organizations supported this recruitment strategy and disseminated the study recruitment documents. Cancer organizations shared the research study and contact details for the research team on their website, their social media (Instagram, Facebook, and LinkedIn sites) and emailed the cancer centers in each state to ask for their support.

Data Collection: Data were collected by one allied healthcare professional and one experienced health service researcher. Both were female, one qualified accredited exercise physiologist and one registered nurse and senior researcher with experience in qualitative research. During each interview reflective field notes were taken. On average the semi-structured interviews lasted for one hour. Patient demographic data were collected prior to the interview and deidentified for confidentiality purposes. Data included age, gender, cancer diagnosis, and treatment information as well as COVID-19 infection status, see [Table 1](#). Neither researcher had any previous relationships with any participant. There was no presence of nonparticipants during any interview. No repeat interviews were conducted.

Interview Guide: The purpose of the semistructured interview guide was to ensure the interviewer remained on topic was also flexible to allow for open two-way communication, which elicited other relevant insights into individual experiences, see [Table 2](#).

Data analysis: Thematic inductive analysis was used,^{25,29} see [Table 3](#) for an overview of the steps in the process. The first stage involved familiarization of the qualitative data and examination of the data for broad themes, which involved reading and re-reading the transcripts. A reflective diary was kept by the researchers during the coding process and noting patterns in the codes. All researchers reviewed and refined the themes until consensus was reached by revisiting the data coded, reflective notes, and the research question to finalize the themes.

Ethics: This project received ethics approval from the University of Canberra Human Research Ethics Committee (Project number:11757). Written informed consent was given by all participants prior to the scheduling of their interview. With verbal consent given again before the interview and audio recording commenced. Participants were free to withdraw from the study at any point without providing a reason. Data were anonymized for privacy and confidentiality reasons.

Results

A total of eight participants consented to take part in this study. Three additional participants consented but did not attend the semistructured interview. Of the eight participants, five were female and three were male, see [Table 1](#). Seven resided in the Australian Capital Territory (ACT) and one in New South Wales (NSW). The average age of participants was 60.8 (± 12.3) years old, six participants lived with their families, and two lived alone. Five participants reported being retired with varying previous employment, while two participants were currently working full-time, and one participant was planning on returning to work in late 2022. Five female participants had breast cancer at varying stages, two male participants had prostate cancer, and two participants had multiple cancer diagnoses (lung, kidney, brain, and bone). Two participants had a self-reported COVID-19 diagnosis, while the remaining six had been a close contact, but never contracted COVID-19.

The findings identified four overarching themes, namely: 1) the impact on accessing healthcare services within both (a) hospital and (b) community-based facilities, 2) encounters with healthcare professionals, in both (a) face-to-face and (b) telehealth, 3) the impact on daily living (a) physically, (b) financially, and (c) family and socially, and 4) the impact of COVID on psychological well-being, see [Fig 1](#) for an overview of the themes.

TABLE 1
Participant Demographic Information.

Participant number	Age	Gender	State	Cancer Diagnosis	Cancer Treatment Details	COVID-19 Status	Marital Status	Children	Location of Home	Living Circumstances
1	70	Male	ACT ^a	Prostate cancer, 2021	Surgery: robotic radical prostatectomy in September 2020 Radiotherapy, January 2021 Chemotherapy April-July 2021 Hormone therapy 3 monthly injection (current September 2022)	No	Married	No	Urban	Townhouse with wife
2	41	Female	ACT	Breast cancer, 2021	Neoadjuvant chemo 1 September 2021 Surgery: mastectomy unilateral with axillary clearance 11 lymph nodes 15 December Radiotherapy: March 2022 Aromatase inhibitors and other hormone therapy. Plan to have ovaries removed at the end of year or early 2023.	Yes	De facto	X2	Urban	House with children and partner
3	71	Male	ACT	Kidney cancer 2011, metastases adrenal gland 2014 and lungs 2015, prostate cancer 2018.	RCC and metastases: treated by surgical removal (kidney and adrenal gland) and chemotherapy therapy for lung metastases Prostate cancer: Radiation therapy 2018, ongoing hormone therapy	No	Divorced	X3	Urban	Lives alone
4	68	Male	ACT	Prostate cancer, 2022	Lucrin: hormone therapy + radiation therapy (no dates provided)	No	Married	X3	Urban	House with wife
5	52	Female	ACT	Breast cancer, 2022	Mastectomy February 2022, followed by chemotherapy	Yes	Married	X1	Urban	Townhouse with husband and son
6	47	Female	NSW	Breast cancer, 2021	Neoadjuvant chemo 6 months: paclitaxel weekly for 12 weeks, carboplatin 3 weekly, Immunotherapy: pembrolizumab 3 weekly. Second 12 weeks. Radiation therapy	No	Single	No	Urban	Townhouse alone.
7	73	Female	ACT	Breast cancer, 2018	Chemotherapy, radiation, and surgery October 2019	No	Married	X2	Urban	House with husband, 1x son and 1 grandchild half the week
8	65	Female	ACT	Brain cancer, lung cancer, bone cancer	Radiation therapy/immunotherapy chemotherapy/surgery/clinical drug trials (dates not reported)	No	Single	X2	Urban	House with mother living in granny flat

Impact on Accessing Healthcare Services

Overall, individuals with cancer shared varying experiences with accessing care, both in hospital and in outpatient facilities, including their general practitioner, dentist, or accessing allied health services. Participants who were diagnosed with cancer earlier in the pandemic generally reported greater concerns with the fragmented scheduling of appointments, reduced access to allied health services, and generally inferior experiences with telehealth appointments, whereas other participants who received their cancer diagnosis later in the pandemic described more positive experiences and found their healthcare teams were more accessible.

"I guess I was pretty lucky the COVID protocols didn't seem to affect me all that badly ... Similarly, when I had the radiotherapy and then the chemotherapy, yes there were protocols in place. Signing procedures, that sort of thing, but it didn't delay any." (Male, 70, prostate cancer)

Hospitals

Most participants reported mixed perceptions of accessing cancer services in the hospital setting. One participant noted:

"I actually felt safe in those environments, even though I was very sick" (Female, 65, brain, lung, and bone cancer)

Whereas another stated:

*"It was awful and scared the s**t out of me"* (Female, 41, breast cancer)

Most of the participants were unable to compare pre-pandemic cancer services to the current pandemic cancer service provisions and were hesitant to draw a conclusion that the COVID-19 pandemic was the sole reason for interruptions and deficiencies in their care. However, one participant expressed shortcomings in cancer care that were long-standing and articulated *"So the things that were bad were kind of habitually bad, I think."* One participant reported having both a pre- and during COVID-19 pandemic care perspective and noted that 2021 was the *"worst and most difficult year."* Many reported that the COVID-19 protocols in hospitals, visitor restrictions, masks, and check-ins were comforting and provided a sense of safety, but others found them distressing and disruptive. Most of the participants reported significant congestion in hospital cancer services, which

TABLE 2
Interview Topic Guide.

Interview Topic Guide
1. In 5 words or less how would you describe your experience during the COVID-19 pandemic?
2. Can you tell me, have there been any changes to your treatment plan across the last two years?
3. Have you had any difficulties accessing healthcare services?
4. If any, which aspects of your care have been most affected?
5. Did you use telehealth for appointments? If so, how did you find it in comparison with face-to-face appointments?
6. Do you have any different feelings associated with attending hospitals/ out-patient clinics for treatment?
7. Did you feel there was a change to the attitude of your healthcare professionals?
8. Were there any changes to the quality of care provided by your treatment team during this time? If so, why do you think this was?
9. Do you think COVID-19 affected your ability to perform daily tasks?
10. Did the pandemic force you to make any changes regarding how you accessed the community?
11. Have there been any changes to your ability to work over the last two years?
12. Did you experience any financial difficulties during the pandemic?
13. Have there been any changes to the way you interact with others, whether it be family, friends, or the wider community across the last two years?
14. What did this experience look like for you?
15. Did this lead to any further circumstances?
16. Can you tell me whether you think the pandemic has affected your family dynamic and if so in what way has it?
17. At any point across the last two years did you find your mental health was impacted?
18. Could you describe what this looked like for you, e.g., coping strategies, symptoms, time frame?
19. Have you experienced any physical symptoms different to pre-pandemic?
20. Do you think that the pandemic has had an impact on your physical well-being?
21. Has the pandemic impacted your ability to participate in physical activity?

TABLE 3
Phases of Thematic Analysis

Phase	Description
Familiarization of Data	Familiarization of data was completed independently by HL, which involved reading and re-reading the transcripts. HL completed post-interview reflections to summarize initial thoughts on collected information and both HL and CP familiarized themselves with the data throughout the interview process.
Generation of initial codes	HL identified initial features of the data which were relevant to the previously defined domains of unmet supportive care and applicable to the research question. CP reviewed the initial codes, and any discrepancies were openly discussed.
Identifying themes	HL reviewed initial codes and began to separate data into each identified preliminary themes. At this stage the data was organized into corresponding themes and demographic data was grouped with data to allow for further analysis. CP reviewed data collection and any discrepancies were discussed openly and rectified if required.
Reviewing themes	HL further refined themes to ensure each extract was accurately representative of the theme. HL and CP re-read data within each theme to ensure it accurately represented the entire data set.
Defining and naming themes	HL developed a graphic to further depict identified themes. Refer to Fig 1.
Writing report	Relevant data were extracted in relation to the aims of this project. A full report was written by HL, reviewed, and edited by CP. Further contributions from KT and PK were received.

resulted in delays to the scheduling of their appointments creating a sense that they had to get out of the hospital quickly.
“a terrible mismanagement of healthcare services” (Male, 68, prostate cancer)

Despite overall negative perceptions, none of the participants reported that there were any delays to their scans; CT or MRI, blood tests, surgery or commencement of treatment once booked. Across all the participants, none reported that their treatments were

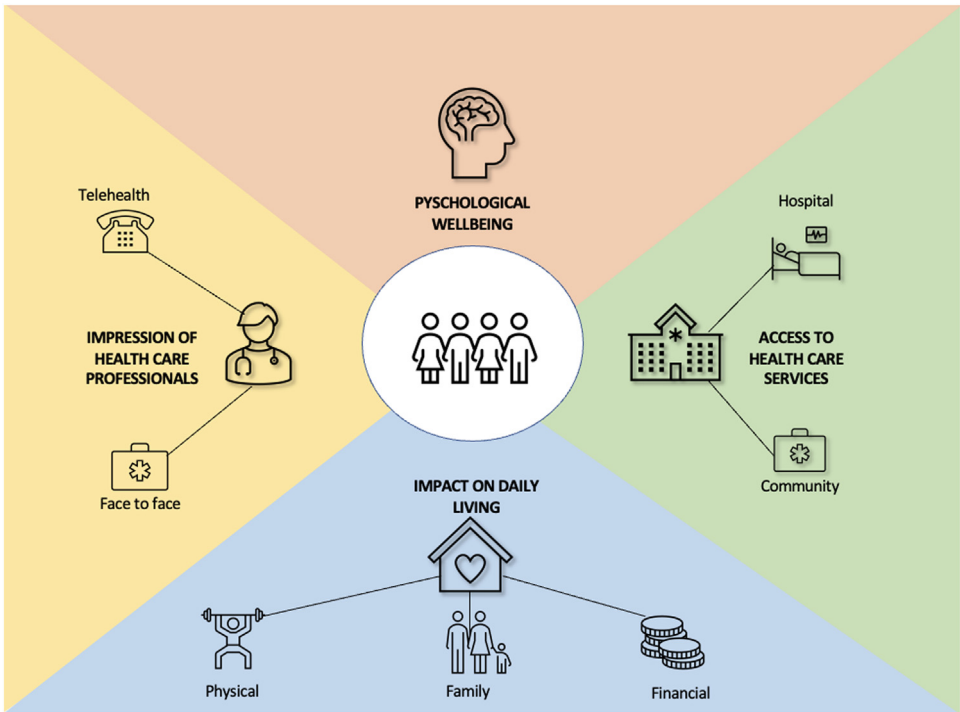


FIG 1. Findings overview.

stopped, canceled, or rescheduled. Only one participant noted a delay to starting chemotherapy treatment, because she was unable to gain access to a breast cancer nurse to undertake the prerequisite educational session.

"Rather uncomfortable as they wanted me to start ASAP" and "Not all of my care was looped in as well as it should have been" (Female, 41, breast cancer).

A further participant had a suboptimal care experience during chemotherapy treatment. She was being cared for by the "at home service" initiated through her contacting the Rapid Assessment Unit and was only able to access direct medical assistance after 8 days, due to the hospitals' directive to reduce people coming into the hospital. Eventually, this participant was admitted to hospital, but at presentation she reported that she was significantly unwell and should have been admitted sooner. In contrast, another participant noted their access to hospital was easy because their treating oncologist provided them with a certificate, which stated they were significantly immunocompromised.

Finally, all participants accessed telehealth appointments at some point during their care. Most of the participants reported that telehealth was a beneficial model, as an alternative to face-to-face consultations. It was important for all participants to have had prior notification that they were being offered telehealth, and that they were comfortable with this mode of service delivery. Notably, only one participant shared their concerns in relation to a lack of a physical assessment during telehealth consultations, which created uncertainty as to whether changes in their condition would be missed. As a consensus across the participants, they found telehealth to be:

"Better than not having anything" (Female, 52, breast cancer)

Community Services

Generally, participants commented that their access to community services was most negatively influenced by the availability of staff, the lockdown rules enforced by governments and the availability of appointments. All participants commented that their GP practices were the most problematic and difficult to access because of the "hard lockdowns" enforced by the government. There were problems with duplication of appointments and inefficiencies with GP services. One participant described having an initial telehealth appointment, followed by an additional face-to-face appointment as requested by their doctor. This led to an increased time spent with the doctor, difficulty scheduling the appointment and additional financial costs to the participant. Other participants avoided attending GP's altogether due to grave concerns about being among sick people. All participants were fully vaccinated against COVID-19 and found accessing this service to be easy with their "vulnerable" status. However, when diagnosed with COVID-19, accessing services was very difficult and problematic due to lack of available services during weekends, multiple COVID-19 helplines were confusing, and it was stressful to require a negative polymerase chain reaction (PCR) COVID-19 test to access the care required. These issues resulted in significant delays in accessing services.

"Relieved to find a COVID specific health clinic eventually but after about 1 week of suffering from an ear infection" (Female, 52, breast cancer)

Those who did contract COVID-19 found accessing the antiviral to be helpful, but similarly a difficult and lengthy task which involved multiple phone calls, with time spent convincing nurses and other healthcare practitioners of their need for the antiviral treatment. Participants said their access to allied health services,

including exercise physiology gym classes, was fine as most offered telehealth services in the height of lockdown. One participant commented that:

"I found them good, Yeah, they weren't as good as being in the gym because I didn't have access to the equipment. So, it was basically a, you know, a chair and some weights and a theraband. But no, I found those exercises quite good because I think, the exercise sessions really did play a big play, in my recovery, and they still do." (Male, 70, prostate cancer)

The only problem with accessing this service was reported to be when staff were sick or forced to isolate due to the pandemic, which meant they could not access any services. People affected by cancer also commented on the need to attend a dentist during lockdown, which became impossible due to the mask mandate.

Participants' Impressions of Healthcare Professionals

All Individuals Shared Positive Experiences and Interactions With Their Healthcare Professionals

Telehealth

Participants shared positive experiences with telehealth, including phone call or video conference with their healthcare professionals. Participants noted that they found telehealth to be better than telephone consultations because telephone calls were "in-personal" and "difficult to build a rapport." All participants found asking questions difficult over the phone or on video call compared to face-to-face consultations, but overall comments were:

"Amazing, they were so familiar with it, very accommodative, even the surgeon, the oncologist helped me turn on the camera and things to enable me to join the conversation" (Female, 52, breast cancer)

And another participant speculated:

"It was all very routine and professional, I suspect there was a difference in the beginning, that's speculation" (Male, 68, prostate cancer)

Face to face

Some participants noted no difference in their treating team, and in fact, attributed the difference to telehealth itself, rather than the individuals. Some noted no change to the quality of care they received, but for others it was the impact of enforcing very strict COVID-19 rules, including visitor restrictions, mask wearing and rapid antigen testing (RAT), which caused some to be frustrated. One participant felt he was rushed from the hospital post-surgery due to a government directive to clear the hospitals as:

"My problem was not seen as great in comparison to the dictate to empty the hospitals" (Male, 73, prostate cancer)

There were mixed perceptions of clinical staff:

"They were all very professional, it didn't matter who, they treated everybody the same" (Female, 47, breast cancer)

While in contrast:

"I think that they were so stressed and running around like mad things, not really knowing what they had to do and doing the best that they could. And because I don't think they had top notch practices in terms of patient centred care at the outset. That meant that when you add extra stress, you revert to type. So that meant that I was even less likely to receive patient centred care, because that

wasn't their baseline. So, I think it exacerbated a problem that I would have experienced already." (Female 43, breast cancer)

Many of the patients reported a lack of care coordination, which were not a direct result of COVID-19, but rather long-standing problems in the healthcare system. Patients also commented on having to advocate for themselves to access these services.

"That's where I really was on my own. And it only happened because I made it happen or because the people around me made it happen" (Female, 43, breast cancer)

Impact of Daily Living

All participants noted interruptions to their activities of daily living. The magnitude of this impact varied between each person and their individual circumstances, whether that was family, location, or timing of their cancer diagnosis. Each participant reported negative feelings toward how the COVID-19 pandemic affected their "normal" way of life:

"Just you know things that you do on the day that we somewhat took for granted before lockdown" (Male, 70, prostate cancer)

However, some shared surprisingly positive anecdotes toward it:

"I'll make one more comment and this is going to sound completely counterintuitive, but I do think that in some ways I benefited from COVID and that's because when I had my diagnosis. Had the COVID lockdown not been in place, we would have been overseas for two months now. That may have delayed my diagnosis, delayed my treatment, resulted in the cancer spreading." (Male, 70, prostate cancer)

Although for the wider public in both the ACT and NSW, COVID-19 appeared to be something of the past, those participants living with cancer noted that they still employ risk reducing behaviors, and commented that post-lockdown is of greater concern than during. As the nonchalant attitudes of the wider public led them to instill long-term behavioral change, taking further precautions, sustaining lockdown provoked changes to their daily living that impacted their friendships and family dynamics.

"I allow them [friends] to visit me, but it's only one or two people each time, but not many of them now because they're aware that my immune system is really low and that kind of thing. so. Ohh Lord, that's significantly impacted me." (Female, 50, breast cancer)

Family and social

Family dynamics were important to participants. Their families were often their main support network and the COVID-19 lockdown forced major changes to this interaction. Most participants commented that they avoided children due to their high infection risk in childcare and school settings. One participant did not care for her grandson, placing added pressures on the parents, others noted home-schooling pressures, while others noted not being able to share the news of a new cancer diagnosis with family in person. Often participants relied on their family members to care for them during treatment, and many commented that when immediate family members contracted COVID-19, this led to a significantly negative impact on them. In relation to their physical care or psychological well-being, as without their support network they felt further isolated.

"Really, I feel really, really done but um, yeah, makes me feel very isolated and feeling really down and I'm just really scared that I was unable to come back to my normal." (Female, 52, breast cancer)

All participants commented on the kindness of family members in delivering care packages and meals to their houses. One commented that they missed their social life, avoided certain social events, and still avoided hugging their friends. While another participant illustrated her gratefulness for the pandemic during her diagnosis as it gave her and her immediate family the time to process it in whatever way they needed to, without succumbing to the pressures to reassure family members, friends or even work colleagues. A participant in NSW noted she only allowed friends to visit if they were fully vaccinated, and because of this they lost contact with one friend, as she refused to get vaccinated.

Financial

The pandemic held significant financial implications for many. Most participants commented on having to use their sick leave and take further measures during treatment, including pre-purchasing leave through salary sacrifices, reduced working hours or not working at all. Many commented that they felt privileged to live in a two-income household and could not imagine being in a situation with only a single income. One participant noted their workplace to be flexible and supportive to allow for a gradual return to work, while another commented that their workplace was unable to provide a safe environment and in turn, they had to take an extended period of leave.

"I think that's the biggest thing I'm pissed off about with COVID, is that I had to exhaust all my leave, when work couldn't provide a safe environment and that's what they're supposed to do. There was no mention of workers comp or COVID leave either" (Female, 47, breast cancer)

Finally, one participant commented on his gratefulness for access to private healthcare, as according to him the public system would have resulted in longer wait times, more interaction with people in hospital waiting rooms and a more invasive surgery, with a longer recovery time:

"I'm very glad I had private health insurance" (Male 70, prostate cancer)

Physical

Changes in access to their community, daily living tasks, and exercise were widely discussed by participants. All participants accessed online grocery and goods deliveries and commented on the widespread shortages and difficulty accessing items as *"you couldn't really go shopping around for things."* However, many felt a sense of comfort in shopping during specific times allocated to those older or immunocompromised. Others commented on sending the "healthier" family member to pick up the shopping when delivery was not an option. Others commented on a reduced access to gyms, exercise physiologists and physiotherapists having negative implications in their symptom management, especially in relation to fatigue during treatment.

"Well, walking definitely ... yeah, because early on you couldn't do it ... because of the difficulty of getting out to gyms and things. So stop doing any gym work." (Male, 68, prostate cancer)

Those who were able to access online gym sessions, did so, but commented on how without access to the equipment, they did not find the same physical benefits. Similarly, participants commented on online church, choir or art classes as great alternatives and felt it met their needs, without needing to be around large crowds.

Impact on Psychological Well-Being

Participants commented that psychologically they found the COVID-19 pandemic to be challenging. Many shared nervous and

anxious feelings toward attending health facilities, accessing their community, interacting with family and or friends, which compounded poorer mental well-being accompanied by a cancer diagnosis.

"It was isolating" (Female, 47, breast cancer)

"I feel really, really done, feeling very isolated, feeling very down and I am just really scared that I was unable to come back to normal" (Female, 52, Breast Cancer)

The visitor restrictions which prevented the support of family and or friends during treatment, pre- and post-surgery or in cancer consultations, were highly distressing and concerning. Being alone without a support person when they received their news of disease progression, or results from scans was confronting and difficult to do without loved ones. Participants also relayed that they worried about their loved ones not being able to hear the news from the medical professionals themselves. When having COVID-19 themselves, participants shared:

"Oh, my lord I was so scared, I was so so scared" (Female, 52, breast cancer)

Consciousness of their immunocompromised status led to increased feelings of worry and stress. When patients had difficulties in accessing antiviral medication, they reported being "freaked out" and "significantly stressed" likened to the first time someone finishes chemotherapy treatment.

*"I am happy to die from cancer, but I'll be f***d if I die from covid, I'm not having it, I said I'm not fighting to live to end up with one of those. And that was probably the most difficult because I felt really isolated." (Female, 65, brain, lung, bone cancer)*

Discussion

This study set out to describe the experiences among people affected by cancer during the COVID-19 pandemic in an Australian context. The findings from this study identify that the evolving elements of cancer care were most profoundly impacted by the pandemic. These were inclusive of exercise prescription during treatment, access to education sessions, telehealth consults, and reduced support networks. It was clear that COVID-19 interrupted the typical functioning of cancer services; especially in out-patient healthcare settings and it was apparent that visitor restrictions in hospitals substantially impacted family support dynamics and patient experiences, although on a positive note, participants reported no appointments were cancelled or rescheduled because of COVID-19. The COVID-19 pandemic interrupted daily functioning for all the participants and described avoidant behaviors post-lockdown, which led to ongoing feelings of isolation, social anxiety, and disconnect from family and friends. COVID-19 forced healthcare professionals, clinical governance teams, and federal health ministers to search for low-risk approaches to allow continued delivery of care and avoid large-scale rises to COVID-19 infection in hospital and outpatient healthcare settings.

These changes to service delivery fast-tracked telehealth as the main model of delivery. This study identified that patients with various cancers all used telehealth at some point in their treatment journey during the pandemic and according to participants it was an acceptable modality of service. While telehealth was noted as a positive practice, confidence in diagnosis because of lack of physical examination, poor rapport through computers, and the ability to solely replace the face-to-face contact with healthcare professionals, were identified as healthcare concerns. As momentum continues to build and supports the provision of telehealth services; it remains

important to consider how telehealth services can be maintained to ensure there are no disparities in care.

Existing research detailing the importance of continued provision of telehealth services, encourages healthcare professionals to seize the new opportunity telehealth holds in practice.³⁰ This research also demonstrated positive patient experiences and interactions with telehealth during the COVID-19 pandemic. While raising similar concerns regarding the need for telehealth to grow and be continually adapted to fit the changing needs of the patient demographic.³¹ Telehealth poses a refreshing and exciting opportunity to further advance the delivery of healthcare and cancer services in Australia; however, it is imperative that future research explores strategies to develop and ensure evidence-based practice, that is patient centered and creates malleable methods of telehealthcare in both urban and remote settings.

Access to GPs during the COVID-19 pandemic was problematic for the participants in this study. Evidence has identified that COVID-19 profoundly affected GPs because the clinical decision-making largely centered on respiratory assessment and triage, and management of long-term conditions, such as cancer was postponed.³² The consequences of the rapid transition among GPs clearly impacted touch points of care in the community setting for the participants in this study. The importance of clear communication and support systems that bridge oncology care and general practitioners is imperative.

Limitations

This qualitative descriptive study has many strengths including a clear and specific methodology, there are, however, several noteworthy limitations. Noteworthy, this study had a small sample size despite extensive recruitment efforts and may limit the transferability of the findings to other contexts. Furthermore, only two patients reported having COVID-19 and it was not possible to discern subtle differences among the participants' experiences of having COVID-19 and those being close contacts. This study also failed to capture participants Australia wide and instead was only able to recruit participants in Eastern regions of Australia. Despite these limitations, the authors followed a transparent method and analysis to improve the rigor and validity of the findings.

Future Implications for Nursing Practice

Although participants in this study described positive experiences with telehealth, it is important to consider their geographical location, socioeconomic status, and level of education in this reflection. As the COVID-19 pandemic held worldwide consequences on cancer practices the findings of this study within Australia may be translated to other settings. The research team supports future research into the sustainability of telehealth services globally that includes people from diverse cultures, geographical and socioeconomic backgrounds, and various cancer diagnoses. Allowing researchers to gain a valuable representation of the supportive care needs experience of all people affected by cancer, provided valuable insights in planning for future pandemics.

Conclusion

The COVID-19 pandemic held significant implications on the experiences of supportive care among people affected by cancer. This study identified the pandemic was disruptive to cancer services, complicating access to care, interruptive to daily life and functioning, and held a significant financial and psychological burden. This study also acknowledged support for telehealth services as a suitable alternative, however careful consideration is required before this becomes a predominant model of care in the future.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Supplementary materials

Supplementary material associated with this article can be found in the online version at doi:[10.1016/j.soncn.2023.151508](https://doi.org/10.1016/j.soncn.2023.151508).

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Supplementary Table 1. Consolidated Criteria for Reporting Qualitative Studies (COREQ) Checklist

No. Item	Description	Reported on page
Personal Characteristics		
1. Interview/facilitator	The author who conducted the interviews.	Page 6
2. Credentials	The researcher's credentials.	Page 6
3. Occupation	The interview's occupation at the time of the study.	Page 6
4. Gender	Male, female, or non-binary.	Page 6
5. Experience and training	Experience and training of the researcher.	Page 6
Relationship with participants		
6. Relationship established	Relationship prior to study commencement.	Page 6
7. Participant knowledge of the interviewer	Knowledge about researcher.	Page 6
8. Interviewer characteristics	Characteristics reported about the interviewer.	Page 6
Theoretical framework		
9. Methodological orientation and theory	The methodological orientation underpinning the study.	Page 4
Participant selection		
10. Sampling	Method of participant selection.	Page 5
11. Method of approach	How participants were approached.	Page 5
12. Sample size	Number of participants in the study.	Page 7
13. Non-participation	Number of participants who refused to participate or dropped out.	Page 7
Setting		
14. Setting of data collection	Location of data collection.	Page 6
15. Presence of non-participants	Presence of other individuals at the time of data collection.	Page 6
16. Description of sample	Important characteristics of the sample.	Pages 23-25 Table 1
Data collection		
17. Interview guide	Interview guide and prompts used.	Page 26 and Table 1
18. Repeat interviews	Statement of whether repeat interviews were conducted.	Page 6
19. Audio/visual recording	Type of interview recording.	Page 4
20. Field notes	Description of field notes made during or after the interview.	Page 6
21. Duration	Duration of the interviews.	Page 6
22. Data saturation	Discussion around data saturation.	Page 6

23.	Transcripts returned	Return of transcripts to participants.	NA
Data analysis			
24.	Number of data coders	The number of data coders who coded the data.	Page 6
25.	Description of the coding tree	Description of coding tree.	Page 26 Table 3
26.	Derivation of themes	Identified in advance or derived from the data.	Page 8, Figure 1
27.	Software	Software used to manage the data.	Page 4
28.	Participant checking	Feedback from participants.	NA
Reporting			
29.	Quotations presented	Participant quotations presented to illustrate the themes.	Pages 8-18
30.	Data and findings consistent	Consistency between data presented and the findings.	Pages 8-18
31.	Clarity of major themes	Major themes clearly presented.	Page 8, Figure 1
32.	Clarity of minor themes	Description of minor themes or categories.	Page 8, Figure 1
