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Experiences of cancer care in COVID-19: A longitudinal qualitative study

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ABSTRACT

Purpose: This study aimed to explore the cancer care experiences of people living with and beyond cancer during COVID-19 in Ireland.

Methods: The study adopted a longitudinal qualitative design using semi-structured interviews with sixteen participants. Interviews were undertaken on three occasions over six months (January–June 2021). The National Comprehensive Cancer Network Distress Thermometer (NCCN DT), and Connor-Davidson-Resilience Scale (CD-RISC2) were also used as part of the interviews to measure distress and resilience. Thematic analysis of interview data was conducted and participants' self-rating for distress and resilience was analysed using descriptive statistics.

Results: Sixteen patients participated. The findings revealed participants' constant fear of COVID-19 over time and efforts to stay safe by following the 'rules'. Isolation was a common experience as COVID-19 restrictions resulted in being alone when attending the hospital for treatment and limited support from family and friends. Telephone follow-up was limited in terms of support and patients' opportunity to ask questions. For a minority, COVID-19 restrictions meant they were 'not missing out'. On average, participants reported moderate to high levels of resilience at all time points. Distress scores were low but trended upwards from T1 to T2.

Conclusions: The findings highlight the need to avoid restrictions on carers accompanying their close relatives to the hospital for treatment. An evaluation of the effects of the rapid introduction of telephone follow-up on patient outcomes is warranted.

1. Introduction

The impact of the COVID-19 pandemic presented significant challenges to cancer services worldwide. Treatment adjustment, delay and discontinuation were reported early in the pandemic (de Joode et al., 2020; Dhada et al., 2021). Cancer screening programs worldwide experienced interruptions (Alkatout et al., 2021). In addition, there were restrictions on surgery and disruptions to clinical trials (Forner et al., 2021; Greco et al., 2021).

Over the course of the pandemic, our understanding of the impact of COVID-19 on cancer is increasing. COVID-19 infection in cancer patients puts them at risk of serious illness and early mortality (Assaad et al., 2021; Fu et al., 2021; Miyashita et al., 2020; Nath et al., 2022; Robilotti et al., 2020; Taghizadeh-Hesary et al., 2021), especially those with haematological malignancies and lung cancer (de Joode et al., 2022) and those with respiratory, endocrine and renal co-morbidities (Al

Bahrani et al., 2021; Zori et al., 2021). Moreover, the severity of COVID-19 infection and previous exposure to ≥ 3 lines of chemotherapy are other main factors associated with earlier death (Péron et al., 2021). There is also clear evidence, that cancer diagnoses were delayed (Dinmohamed et al., 2020), a trend expected to continue in the short term (Alkatout et al., 2021). This will lead to longer-term consequences such as an increase in newly diagnosed patients with advanced stages of cancer and avoidable cancer deaths (Alkatout et al., 2021; Forster et al., 2021; Maringe et al., 2020). However, the avoidable cancer deaths due to COVID-19-related interruption to services will probably not be known for a decade or longer (Sud et al., 2020).

A number of qualitative and mixed methods studies worldwide have explored patients' experiences during COVID-19, including in Denmark (Dieperink et al., 2021), the US (Hyland and Jim, 2020; Sokas et al., 2021), Canada (Forner et al., 2021; Galica et al., 2021; Kilgour et al., 2021; Savard et al., 2021), India (Dhavale et al., 2020), the UK (Radcliffe

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et al., 2022), Australia (Page et al., 2022) and Turkey (Göral Türkcü et al., 2021; Seven et al., 2021). However, our understanding of cancer patients' experiences, in particular, the evolution of the experience over time during COVID-19 remains limited. This study aimed to describe the experiences of people living with and beyond cancer and caregivers' experiences of cancer care in Ireland during COVID-19 over a six-month time period. Longitudinal qualitative research is ideal for exploring experiences of change and stability over time (Calman et al., 2013).

2. Methods

2.1. Design

The study adopted a longitudinal qualitative design. The interview schedule also asked participants to rate their level of distress and resilience. A detailed account of the study design is provided elsewhere (Drury et al., 2021). The SRQR (Standards for Reporting Qualitative Research) guided reporting of the study (O'Brien et al., 2014).

2.2. Recruitment and sample

Adults living with a cancer diagnosis (melanoma, breast, prostate, lung, colon) living with or after cancer, and their caregivers, were invited to participate via cancer-related social media platforms. Recruitment commenced in December 2020 and the first round of interviews was held in January 2021 (Table 1). Twenty-two people expressed interest in participating. Two did not meet the study's inclusion criteria, three did not return consent forms and one withdrew the day before their arranged interview.

2.3. Data collection

Participants were interviewed on three occasions over six months (January–June 2021), capturing their experiences against the evolving political and socio-cultural context of COVID-19 in Ireland (Table 1). Fifteen participants participated in all three planned interviews. One

Table 1
Interview timelines and context.

Phase	Time 1	Time 2	Time 3
COVID-19 context	January 18th – February 17th, 2021	March 31st - April 20th, 2021	May 28th - June 25th, 2021
	<ul style="list-style-type: none"> •High COVID-19 incidence and mortality rates. •Third National lockdown. 	<ul style="list-style-type: none"> •Reducing COVID-19 incidence and mortality. •Some easing of COVID-19 lockdown restrictions. People allowed to travel within their own county or within 20 km of their residence if crossing county boundaries •Vaccination programme underway but numbers being vaccinated low due to supply issues •People with cancer receiving initial vaccination. 	<ul style="list-style-type: none"> •Low COVID-19 incidence and mortality. •Vaccine roll-out extended to those aged in their 40's •Restrictions on movement eased but the very hot weather meant crowds were meeting outdoors prompting some social unrest. Police intervening to clear large groups of young people. •Pubs and restaurants opening for outdoor dining. •People with cancer vaccinated.

further participant was interviewed on two occasions but was unable to participate in a final interview due to acute illness. Fifteen participants were interviewed by telephone and one by Microsoft teams. All interviews were audio-recorded and transcribed verbatim. The first author, an experienced qualitative researcher with a clinical background in cancer nursing, conducted all interviews (n = 47) and recorded reflexive notes after each interview.

A detailed account of the data collection methods, including the interview guide and preliminary findings (T1 interviews), are reported elsewhere (Drury et al., 2021). Briefly, semi-structured interviews were conducted to explore participants' views and experiences of their cancer of care, information needs, and concerns relating to COVID-19 over a six-month period. Participants' self-reported distress and resilience were measured at each time point using the one-item National Comprehensive Cancer Network Distress Thermometer (NCCN-DT) and the 2-item Connor-Davidson Resilience Scale (CD-RISC2). Interviews were recorded, transcribed, and all participants were offered a copy of their interview transcripts and provided an opportunity to amend or clarify their transcript at each time point.

2.4. Data analysis

The protocol for data analysis has been reported elsewhere (Drury et al., 2021). Briefly, qualitative data were analysed cross-sectionally in NVIVO by the first author and verified by the final author. Thematic analysis guided the approach to analysis (Braun and Clarke, 2006). A summary of the cross-sectional thematic analysis informed subsequent interview guides at T2 and T3. All participants were sent a summary of key findings before T2 and T3 interviews. Following T3, analysis of all interviews was undertaken according to the principles of trajectory analysis, capturing changes in experiences over time (Grossoehme and Lipstein, 2016). Participants' distress and resilience scores were analysed descriptively.

2.5. Ethical considerations

Ethical approval for the study was granted by the University Research Ethics Committee (Ref: R20.Jun.04 (REC University of Galway, Ireland)). All participants provided written informed consent prior to the first interview and continuous verbal consent was attained before the second and final interviews.

3. Results

Of the sixteen participants interviewed, one was male. Most participants had a diagnosis of breast cancer (n = 12) and most (n = 9) were in remission at the time of T1 interviews (Table 2).

3.1. Themes developed

Participants' experiences were organised into three themes (with subthemes) (Table 3). The subtheme 'vaccination protects' was the only new code arising from analysis between Time 1–3.

3.1.1. Theme 1: Being careful, keeping safe and feeling safe

All participants believed in being careful to avoid infection. Only one participant mentioned vaccine hesitancy. The additional risk posed with COVID-19 caused fear and anxiety. However, visits to hospitals were perceived as safe and participants were appreciative for the minimum interruptions or delays to their cancer treatment.

3.1.2. Following the rules

Participants were careful to follow the guidance on hygiene, social distancing, and mask-wearing. This attention to the rules remained unchanged throughout the interview time points.

[...] we're clean, we have to extra sanitise and to do 3 h cleaning

Table 2
Participant characteristics (n=16).

Characteristic	Response	n
Participant	A person with cancer	15
	Family member and caregiver	1
Age groups	18–40	5
	41–60	10
	61–80	1
Gender	Female	15
	Male	1
Living arrangements	Living with family member(s)	15
	Living alone	1
Diagnosis	Breast cancer	12
	Colorectal cancer	3
	Lung cancer	1
Time since first diagnosis	6–12 months:	10
	1–2 years	1
	2–3 years	1
	3–4 years	1
	4–5 years	1
Disease Status	Receiving treatment	5
	For recurrent disease	2
	In remission	9

Table 3
Findings from the interviews.

THEMES	SUBTHEMES
Being careful, keeping safe and feeling safe.	Following the rules Hospitals feel safe Vaccination protects
Shrinking supports, feeling isolated and being silenced	Isolated from family and friends Finishing treatment Being silenced
Not missing out	Everybody is in the same boat Privacy in the cancer experience

extra that I never did before. (P7, T1)

For some “manic cleaning of the groceries [was] increasing stress levels” (P5, T2). Fear drove participants’ diligence in following the rules; “I was frightened [...] I’m cleaning my hands continuously. (P15, T3)

Lockdown rules also meant not seeing family and for those with children, it was a challenge.

I think keeping the kids away from other children that was probably the biggest challenge to be quite honest that we experienced [...] We were trying our best to keep them away from other people. We were told you know that was important. (P3, T1)

Participants having chemotherapy were very careful to limit their only visits outside the home to the hospital.

I was very careful I mean I didn’t go into a shop from March until [...] probably October or November even. (P4,T1)

For a few participants, COVID-19 meant they felt “safe” in their home and “people can’t be popping around” to visit (P12, T1). It also made it easier “keeping yourself safe and away from people [when having chemotherapy]” (P11, T3)

3.1.3. Hospitals feel safe

All participants noted the efforts being made to keep them safe on hospital visits. Participants felt “reassured” (P11, T1) on finding their hospital appointments “very safe” (P16, T3) and that “every precaution was being taken” (P16, T1).

I felt safe enough, they were all wearing their masks and their gloves and I found the whole place spotless as well. [...] it’s [COVID] had made people more hygienic. (P2, T1)

You felt very, very safe. So then it was just a matter of getting your chemo and getting home. (P12, T1)

‘[...] you go in [for radiotherapy] and there’s no waiting around, no

queue, space around you (P3, T3)

[...] people are more spaced out and in one room there’s probably 12 chairs I suppose for the waiting room and there’s only 2 people there with 12 chairs, so they had them all well-spaced out. (P2, T3)

COVID wise I felt very safe, it didn’t really entered my head to be honest. Once I was inside the door you know I just trusted in those (P16, T3)

Participants’ experience of ‘feeling safe’ included being “prioritised more” (P3, T1) with no delays in referral or treatment.

[...]there hasn’t been any delays whatsoever. In fact nearly the opposite. Whenever I’ve needed care or been referred I’ve gone straight in within days. (P6, T1)

Every single day of that week I had appointments in the hospital. I was actually overwhelmed with everything that was coming at me. There were no delays. (P8, T1)

I was referred to her [oncologist] within a week of being diagnosed. (P14, T1)

With social distancing and the timing it’s so quick that people aren’t really hanging around at all. And they don’t want you to be, I mean they advise that you stay in the car, ring in and then they’ll call you when you are able to walk straight in. (P6, T2)

I’d be getting the radiotherapy so procedures were very similar, you know you go in and there’s no waiting around, no queue, space around you, yeah. (P3, T3)

3.1.4. Vaccination protects

At the time of the participants’ second interview (T2, March–April 2021), three participants had received two vaccine doses, six had received a first vaccine dose and six were anxiously waiting to be called for their first vaccine. “[...] vaccination is the only way to feel protected”. (P4, T2). Having the vaccine meant feeling “more confident” (P3, T2)

Only one participant had decided that they would not take the vaccine when offered:

I probably won’t take it. I’ll wait till I see how everyone else does on the vaccine. Because I suppose I’m in remission and I don’t want to activate my cancer. (P8, T2).

By June, the time of the final interviews, eleven participants were fully vaccinated and four were awaiting their second vaccine dose. Being vaccinated was described as “almost the equivalent to winning the lotto” (P1, T3). Participants talked about their vaccination with positivity, hopefulness, and optimism.

I have to say I’m pretty good at the moment given that I’ve had my vaccination and so while I’m still mindful of the possibility of infection, I suppose my fears would be considerably less [...]. (P11, T3)

It’s great to have had the first one [vaccination] it’s definitely after making me feel much better about you know the worry and risk of infection, definitely. (P13, T3)

3.2. Theme 2: Shrinking supports, feeling isolated and being silenced

COVID-19 restrictions meant being alone when attending hospital. Restrictions prevented visits to the home by family and friends. Moreover, the wider support services offered by local cancer support centres ceased. Follow-up appointments were replaced with telephone consultations.

3.2.1. Isolated from family and friends

Participants’ sense of isolation was most strongly felt at the first interviews. Restrictions meant being alone when attending hospital. The first day of treatment was “incredibly frightening” (P11, T1)

I found my first session really, really stressful. I was crying coming home and I was never going back again. I found, I hated it, I hated every minute of my radiotherapy. (P 5, T1)

[...] you’re dropped at the door effectively and you can go no further with anyone. (P6, T1)

For the one carer participant, their father was admitted as an emergency and when sitting on a chair waiting for a bed he phoned his

daughter “because he was freezing cold in a place where he was, and I’d have to try and ring [the unit] to see was there anyone that could give him a blanket. (P5, T1)

Not having access to family and friends was described as “the worst thing that happened this year” (P3, T1). Participants described having “no support [and suffering] in silence” (P7, T1). Some felt adrift: “I didn’t know who to tell or what to do” (P9, T1).

[...] I’m missing it [seeing family] more than I was because this has gone on too long ... I’m just finding that difficult, I want to be able to see my family (P5, T2)

At the second interviews, with vaccinations commenced, the hope of seeing family and friends again was a reality:

“there’s a lot of close friends [...] who I haven’t seen now in well over a year [...] I mean keeping in touch on the phone and you know the odd zoom call and that kind of thing is great [...] it’s better than nothing for sure. But it’s kind of you know would be nice to hopefully now in the summer you know maybe try and get to see people face-to-face maybe after now the vaccinations get rolled out a bit more and that kind of thing. I mean certainly just even seeing my mum now [...] I haven’t seen her now since August. (P4, T2)

In the first and second interviews (T1 and T2) many participants talked about missing the support services offered by local charity-run cancer centres. Their sense of missing the “great social aspect” to “just sit down and talk to other people” was keenly felt (P5, T2). Not having this extra support was “an extra layer again on a cancer patient” (P7, T2). The ongoing lack of support services was only highlighted by one participant in the final interview who acknowledged that charities were “trying their best [...] of moving things on line but it’s not the same and I think it just makes it harder” (P14, T3).

The small number of participants who did avail of the online or phone counselling services and support programmes offered by cancer support organisations found this very supportive.

It was the most amazing session; it was the best I felt in months. (P8, T1)

[counselling] really helped me because in the middle of chemo I just wasn’t in a good place mentally. (P11, T1)

I reached out to the Marie Keating Foundation and their Survive and Thrive program [...] it was done online [...] You know you would think maybe online that you mightn’t form the same kind of bond but we had zoom meetings every week and then we kind of set up our own WhatsApp group and everybody had their own story to tell. But everybody’s fears were you know the same ... I found that kind of support to be really, really good. (P11, T2)

3.2.2. Finishing treatment

Over the course of this study, several participants completed treatment; which was described as “a sharp end” (P16, T2), “falling off a cliff” (P3, T2), “a massive anti-climax” (P6, T2) and being “dumped out” (P5, T2). The sudden shift from the end of treatment to waiting for follow-up was experienced as “a big gap”. (P4, T1) with the “safety net” of regular appointments gone (P13, T2).

However, some participants did acknowledge that their feelings of loss following the end of treatment would be there even if COVID wasn’t part of the experience.

[...] it [end of treatment] has to happen. COVID or no COVID I think all these anxieties would be here you know. (P3, T2)

While few participants experienced delays in appointments related to treatment at T1, at subsequent time points, some participants described delays in follow-up examinations, which they had to contact their oncology service to request.

[...] some of my follow-up testing has been delayed by COVID. Now I should have had mammogram, ultrasound at twelve months and I still haven’t had it. [...] I had to make a phone call and say you know what’s happening, what’s the story I’m due to have these [...] (P11, T2)

3.2.3. Being silenced

A small number of participants shared experiences at the first interview where they felt “forgotten” (P1, T1) and “lost” (P5, T1) in their care experience, and that COVID-19 dominated HC professionals’ care

agenda. In the subsequent interviews, with restrictions easing and vaccination roll-out, participants shared dissatisfaction with all follow appointments being virtual and wanted some in-person appointments. For most, telephone or virtual consults were considered “a waste of time” (P8, T2) and “not very supportive” (P3, T3).

[...] there’s no reason why I couldn’t have seen him [oncologist] face to face this time (P3, T3)

I was very surprised to get a virtual appointment, particularly for my first appointment. And anyway there’s other issues that needed to be looked into and I requested that I be seen in person [...] (P14, T2)

[...] in my head I’m worried that it might be a bit of skin cancer. But like I can’t, I want the oncologist to see it but I can’t get to the oncologist to see it [...] (P8, T2)

I would rather if I’m honest the face to face [meeting] (P13, T3)

Telephone consultations were also described as “pretty brief” and “unless you have something specific you want to bring to the conversation there won’t be any other information forthcoming” (P4, T3).

[...] that [in person consults] is definitely something I miss out on [...] when you are on the phone with them you know how busy they are and your little questions seem irrelevant. (P12, T2)

3.3. Theme 3: Not missing out

For some, restrictions on social interaction and travel meant they were ‘not missing out’ and value was placed on having some control in dealing with cancer privately.

3.3.1. Everybody is in the same boat

For some participants, having cancer during COVID-19 when lockdown measures were in place was viewed as a “blessing” (P8, T1), because it was “a challenging time for everybody” (P3, T1). Everyone was “in the same boat, we were all at home,” (P13, T3).

[...] you haven’t missed out as much, some of the bigger, the holidays, some of the events because everybody has missed out on it (P14, T3)

I think like COVID was good to me in a way. Because I didn’t see myself as missing out on much everybody was kind of in lockdown, nobody could go anywhere. (P16, T3)

3.3.2. Privacy in the cancer experience

There was also some comfort when “completely bald” of not having “to go anywhere so nobody” could see (P9, T1).

We [husband and children] didn’t have to go, we didn’t need to go anywhere. And nobody could come in. (P12, T1)

In addition, for some, there was also some control over the disclosure of their cancer diagnosis.

[...] I’ve been able to manage the amount of people that know about my cancer diagnosis and (P6, T3)

[...] strangers, relative strangers I’d rather not have a conversation with them [about cancer diagnosis] so I suppose it [COVID-19] saved me from that, that’s for sure. (P3, T2)

3.4. Distress and resilience

Participants’ high levels of resilience were reflected in the interview findings. On average, participants reported moderate to high levels of resilience at all time points, with a mean CD-RISC2 score of 7.1 (SD, 1.5) at the final interview (Table 4). Most participants talked about being able to cope with change. This is clearly highlighted in one participant’s view: “I think for myself I kind of feel I’m a lot stronger than I thought I was and more resilient than I thought I would. If I had known this was coming [having cancer during COVID-19] I don’t think I would have rated myself as kind of getting through it as well as I did. And I think that’s been really positive for me, just feeling that way”. (P13, T3).

Most participants did not experience severe distress, but the mean NCCN DT score of 4.7 (SD, 2.9) was highest during T2 interviews (Table 4). The timing of T2 interviews coincided with the easing of

Table 4
Distress and resilience scores.

	Mean	SD	Median	Change	Overall Change
CD-RISC2					
T1	6.5	1.6	6.5		
T2	6.6	1.7	8.0	0.1	
T3	7.1	1.5	6.0	0.7	0.7
NCCN-DT					
T1	3.4	2.2	3.5		
T2	4.7	2.9	4.0	1.3	
T3	3.1	2.5	2.5	-1.6	-0.5

lockdown restrictions and the commencement of the vaccination programme. By T3 distress scores had returned to levels lower than T1 on average, demonstrating lower levels of distress on average (Table 4). By T3, participants had all received at least one vaccination, and public health restrictions had continued to ease. This relief is expressed by one participant: “The vaccination has made a huge help to me, even though there was a lot of protection after one, I still wanted to get the second one so that I was kind of done and dusted and you know let me move on to the next part”. (P9, T3).

4. Discussion

The study findings reveal that levels of distress were low to moderate on average among participants. Low distress levels among cancer patients have also been reported in Denmark (Dieperink et al., 2021) and Canada (Galica et al., 2021). Cancer itself is the main cause of worry and distress for patients (Toquero et al., 2021; Dieperink et al., 2021; Hyland and Jim, 2020) and is perceived as a greater threat than COVID-19 (Chia et al., 2021). Unsurprisingly, the study findings reveal participants’ fear of getting COVID-19 and their efforts to stay safe were sustained, even as vaccinations were introduced, and public health measures eased. Cancer patients’ fear of COVID-19 infection is reported widely (Biagioli et al., 2021; Colomer-Lahiguera et al., 2021; Edge et al., 2021; Göral Türkcü et al., 2021; Jeppesen et al., 2021; Leach et al., 2021; Lou et al., 2020; Seven et al., 2021) and they ensured to minimise their risks of getting COVID-19 by staying at home and maintaining recommended hygiene practices (Chia et al., 2021; Dieperink et al., 2021; Hennessy et al., 2021; Hyland and Jim, 2020; Miaskowski et al., 2021; Savard et al., 2021; Seven et al., 2021).

Participants in our study found telephone follow-up limited in terms of support and their opportunity to ask questions, and confusion was expressed by some participants who continued to receive virtual consultations as lockdown restrictions eased. European guidelines informing cancer care during the COVID-19 pandemic included a key recommendation to reduce outpatient visits without endangering patient care (ESMO, 2020). A survey of clinicians (n = 108) from 70 countries reported that outpatient telephone consultations increased by 7.7 fold (Chazan et al., 2020). Reduction in outpatient follow-up visits was the most prevalent treatment modification in the early phase of the pandemic (Powis et al., 2021), accompanied by a rapid introduction of digital communication (de Joode et al., 2020; Powis et al., 2021). The shift to digital communication has been heralded as a ‘silver lining’ for cancer care (Lombe et al., 2021), and welcomed by some patients (Fraser et al., 2022; Hasson et al., 2021; van Erkel et al., 2022). However, this and other studies have demonstrated that some cancer patients are less satisfied with emotional support during telephone consultations (Bultz and Watson, 2021; Christiansen et al., 2022; Gotlib Conn et al., 2021; Kilgour et al., 2021; Page et al., 2022), find it less personal (Zomerdiijk et al., 2021) and are more likely to forget to ask questions (Gotlib Conn et al., 2021).

Clinicians internationally have raised concerns that the increase in telephone consultation would impact patient survival (Chazan et al.,

2020). It is argued that the rapid integration of virtual cancer care “without the aid of a standardized distress screening tool was akin to a natural experiment” (Bultz and Watson, 2021, p.7537). Patient outcomes as a result of the increase in virtual care delivery are unknown (Powis et al., 2021). Therefore, it is essential that an evaluation of the rapid adoption of virtual care on patient outcomes is undertaken to inform sustainable models of cancer care in the future (Meti et al., 2020).

Some participants valued the privacy gained due to restrictions. This finding was also reported in a Turkish qualitative study where women found their efforts to keep their cancer private was helped by wearing a mask (Göral Türkcü et al., 2021). Other participants found the lockdown restrictions helped keep them safe and they felt they were not ‘missing out’. This may be explained by most participants in our study being in remission at the time of the first interviews. For others however, time taken away due to restrictions was experienced as time lost (Hyland and Jim, 2020; Radcliffe et al., 2022). Isolation arising from restrictions was attributed to loneliness when alone in hospital for treatment, a finding reported elsewhere (Leach et al., 2021; Hyland and Jim, 2020; Kilgour et al., 2021; Savard et al., 2021). However, participants in our study did reveal feeling safe on hospital visits and appreciated the measures introduced in response to COVID-19, a sentiment also expressed by cancer patients in Singapore (Chia et al., 2021) the US (Hyland and Jim, 2020; Leach et al., 2021) and Canada (Forner et al., 2021; Gotlib Conn et al., 2021; Savard et al., 2021). However, questions on the emotional impact of being alone for treatment have been raised (Hyland and Jim, 2020; Leach et al., 2021; Radcliffe et al., 2022). In future pandemics, all efforts should be made to minimise restrictions on carers, and if not possible to accommodate, offering telephone conferencing to allow caregivers to be present at consultations should be arranged (Haase et al., 2021; Radcliffe et al., 2022).

Some participants referred to ‘manic’ cleaning at the beginning of the pandemic and found this stressful. Similarly, in a Canadian qualitative study, women talked most about the ‘extra cleaning’ following Quebec authorities’ advice about washing anything that had come from outside the home, including groceries (Savard et al., 2021, p.5724). The “extreme caution” around hygiene and cleaning is also described as “exhausting” by one participant receiving treatment for breast cancer in a Turkish qualitative study (Göral Türkcü et al., 2021). Moreover, in another qualitative study with women survivors of breast cancer interviewed in Turkey, lymphedema, a new physical symptom was reported due to the additional household chores that had to be undertaken (Seven et al., 2021).

Vaccine hesitancy was expressed by only one participant in our study. In the second round of interviews, Ireland’s national vaccination roll-out was well established (April 2021) and most participants were fully vaccinated by the final interviews (June 2021). COVID-19 vaccine uptake in Ireland has been high with 84% of Irish adults fully vaccinated on October 28th 2021 (Central Statistics Office, 2021). However, vaccine hesitancy among cancer patients has been reported elsewhere (Barrière et al., 2021; Chun et al., 2021; Brodziak et al., 2021; Villarreal-Garza et al., 2021; Hong et al., 2022; Admasu 2021; Forster et al., 2021), and is associated with a lower level of education among other factors (de Sousa et al., 2022).

For most participants in our study, not being able to meet family and friends was an isolating experience. Cancer patients internationally report loneliness associated with COVID-19 restrictions (Biagioli et al., 2021; Forner et al., 2021; Hennessy et al., 2021; Edge et al., 2021; Leach et al., 2021; Radcliffe et al., 2022; Savard et al., 2021; Zomerdiijk et al., 2021). Many participants in our study also experienced isolation due to the interruption in services offered by local charity cancer centres. Cancer charities play a significant role in supporting cancer care and the COVID-19 restrictions removed the “comfort and support” offered by cancer support groups and impacted patients’ quality of life (Greco et al., 2021, p.4).

Some participants in our study experienced disruption to follow-care

care. During COVID-19, disruptions, delays and cancellations to follow-up care, have also been widely reported (Leach et al., 2021; Savard et al., 2021). No participant experienced disruption to their cancer treatment. However, delays in treatment have been reported internationally due to treatment cancellations, lockdowns and COVID-19 testing requirements (Dhada et al., 2021). Even a four week delay in curative cancer treatments for seven cancers is associated with increased risk of death (Hanna et al., 2020) and delays in patients' cancer surgery has caused "substantial distress" (Forner et al., 2021, p.1875).

4.1. Limitations

Our study has several limitations. Most participants were in remission, most were women with breast cancer and the sample was homogenous in terms of ethnicity. In addition, only one male participant was interviewed and only one participant had advanced cancer. Moreover, all participants were recruited following information accessed on cancer social media sites; the participant group, therefore, are not representative of all cancer patients.

5. Conclusions

Late January 2022 signalled an endemic phase in COVID-19 with major lifting of restrictions in Ireland, the UK, and other European countries. Preparations for future pandemics are underway (Peelen et al., 2021). In the meantime, the lessons learned from the experiences of people living with a cancer diagnosis during COVID-19 must not be wasted. The use of digital communication will remain but its introduction was rushed and now needs to be evaluated to determine its effects on patient outcomes. Finally, in future pandemics, all efforts to avoid restrictions on carers accompanying their close relatives for hospital and outpatient appointments must be made a priority.

Declaration of competing interest

None declared.

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