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## Older survivors of cancer in the COVID-19 pandemic: Reflections and recommendations for future care

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### ABSTRACT

**Purpose:** Although the year after cancer treatment is challenging for all cancer survivors, older adults ( $\geq 60$  years) face additional challenges due to age-related decline and high rates of comorbidity. There is a paucity of research on how health service interruptions from the COVID-19 pandemic have impacted the experience of older cancer survivors. In this study we explore older cancer survivors' reflections on the pandemic and their suggestions for future care delivery when traditionally offered resources are not available.

**Methods:** We conducted 1:1 telephone interviews with adults 60 years and older previously diagnosed with breast and colorectal cancer and recently ( $\leq 12$  months) discharged from their cancer care team. We analyzed the data using descriptive thematic analysis.

**Results:** The mean sample ( $n = 30$ ) age was 72.1 years (SD 5.8, Range 63–83) of whom 57% identified as female. Participants described personal and societal implications of the pandemic that affected their ability to navigate social support, and public and clinical landscapes. These reflections informed their suggestions for future health care delivery, such as how they could have been better prepared to self-manage their post-cancer treatment journey. Participants recommendations were grouped into four sub-themes: 1) enhanced baseline information; 2) facilitate caregiver support and engagement; 3) greater technology integration; and 4) sustained use and public appreciation of personal protective equipment.

**Conclusion:** Older cancer survivors appreciate the needed shift to virtual appointments and services during the COVID-19 pandemic. Specific strategies to bolster older adults existing strengths and improve their readiness to engage in these measures are critical.

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### 1. Introduction

The SARS-CoV-2 pandemic (herein called COVID-19) has created massive disruption in societies and health systems worldwide [1,2]. In cancer care, there have been reports of delays to cancer treatments and interruptions in services available to support people living with cancer and post-treatment challenges [3–6]. Special attention has

been paid to older adults during this pandemic due to the awareness that COVID-19 is more likely to have catastrophic mental [7,8] and physical health effects for those over the age of 60 [9]; this places older adults with cancer in a doubly vulnerable position. As a result, older adult cancer survivors may be more susceptible to the negative implications of social isolation associated with the 'physical distancing' requirements to reduce the spread of COVID-19 [9]. Given the prevalence of cancer among older adults, the potential psychosocial implications of the COVID-19 pandemic among older adult cancer survivors are worth further exploring in light of identified gaps in the literature [10,11].

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The first year following cancer treatment is a critical period for support and follow-up for older adults who cite a number of challenges, such as physical, emotional, practical, and lifestyle adjustments [12]. Older adults also report challenges with the requisite self-managed nature of cancer – which refers to individuals capacity to manage both acute and often long-term sequelae [13]– due to the complexity of their conditions which often include multi-morbidity [14,15]. In Canada, the delivery of cancer survivorship services and follow-up or surveillance care vary widely [16–18], are largely determined by the type of diagnosis and treatment received, and availability of local resources for care. In the Canadian region where this study took place, an outbreak of COVID-19 occurred in June 2020 (prior to the start of data collection for this study) [19], which led to enduring restrictions in healthcare services, reductions in routine (non urgent) in-person appointments, and wide-sweeping bans on visitors in acute care settings [20]. At the time of this study, the first wave was coming under control in Canada, but no national policies for shielding older adults and those clinically vulnerable to COVID-19 (as in other countries [21]) had been implemented.

The pandemic-related interruptions in services, changes to formal and informal post-treatment supports, and increased reliance on technology and virtual consultations [22] may pose unique challenges to this population of older adult cancer survivors; however, little is known about the unique concerns of older adults with cancer in the post-treatment survivorship period during the pandemic. We undertook the following descriptive study with two objectives: (1) to report reflections on the pandemic shared by older adult cancer survivors; and (2) to understand their suggestions for suitable resources and delivery methods when traditionally offered resources are limited or unavailable.

## 2. Methods

In this report, we describe qualitative findings from a convergent mixed-methods [23] (QUAL+quan) study wherein we used a descriptive qualitative research approach [24]. Findings of the full study, which reports coping responses (as defined by Moos and Holahan [25]) used by older adult cancer survivors during the pandemic, are reported elsewhere [26].

### 2.1. Sample & sampling

Participants' contact details were drawn from a database of community-dwelling older adults previously diagnosed and treated for breast or colorectal cancer (including chemotherapy, surgery and/or hormonal therapy) and consented to be contacted for further research conducted by the senior author (JG). We used a purposive stratified sampling approach to focus on those at greatest risk for COVID-19 (e.g., age categories 60–69; 70–79, and ≥80 years) and mailed a consent form and study information between June and July 2020. Interested participants contacted JG to make arrangements to complete a telephone interview. All participants consented to have demographic and clinical information (e.g., age, marital status, work status, ethnicity, diagnosis, and treatment) extracted from the participant database and included in the present study.

In alignment with our qualitative approach, we recruited participants who had been discharged from the care of their cancer team in the preceding 12-months. We sought to recruit a balance of men and women and age stratum to add to the diversity of perspectives. Using a concurrent analysis approach, we sought new participants until we noted repetition in the developing themes through analysis and a solid description of the phenomena [27]. This study was approved by the Research Ethics Board of Queen's University (HSREB#6030148).

### 2.2. Data collection

Qualitative data was collected using a series of semi-structured open-ended questions via 1:1 telephone interviews with an experienced

qualitative researcher (JG or KH). A sample of the questions posed are in the Supplementary Information. The interviews, which took place between July and August 2020, lasted between 25 and 60 min, were digitally recorded and professionally transcribed.

### 2.3. Data analysis

We used descriptive thematic analysis to describe patterns and meanings in the experiences and narratives of participants with an emphasis on robust description versus counting and weighting [24,28,29]. Two team members (JG, KH) engaged in the qualitative data analysis using NVivo 12, with weekly meetings to discuss the developing coding framework and impressions of the data. Our iterative approach to data analysis included reading transcripts to determine initial codes, grouping codes into sub-themes and then into broader themes until consensus was reached to provide an inclusive description of participants' perspectives. Throughout analysis we revised the framework and organization of codes until we agreed on the structures and definitions. We used SPSS version 26 for descriptive statistics of participant demographics. To ensure a rigorous approach to this study we adhered to the principles of epistemological integrity, analytic logic, interpretive authority, and representative credibility [30].

## 3. Results

Thirty older adults with cancer (17 [56.7%] female, 13 [43.3%] male), who were an average 72.1 years of age (SD 5.8, Range 63–83 years), took part in the study. Equal numbers of participants had been diagnosed with breast or colorectal cancer, and 19 (63.3%) and 11 (36.7%) of participants lived in urban and rural areas, respectively. Additional details about the study cohort are provided in Table 1.

Overall, older cancer survivor participants felt that they were coping well during the pandemic in the face of restrictions to healthcare services and newly imposed visitor policies. However, participants reported having to adapt to the changing landscape of healthcare delivery to manage their ongoing cancer and health-related survivorship challenges as well as give and receive social support. Herein, we describe two descriptive themes from the data: 1) reflections on the pandemic; and 2) suggestions for future care delivery.

### 3.1. Reflections on the Pandemic

Although participants felt “restricted” by the pandemic (e.g., unable to travel or engage in formerly enjoyed social activities or dining out at restaurants, and unable to see their clinician in-person for non-urgent reasons), older cancer survivors respectfully accepted these restrictions. One participant stated: “*The pandemic, it's got its ground rules. And either you're going to abide by them or say the hell with it. We abide by them*”. Nevertheless, many older cancer survivors regarded the pandemic as a time for reflection, whereby “*something good has to come out of this. This has happened for a reason*”. Participants articulated these reflections as having personal and societal implications, as well as their own challenges with navigating social support, public, and clinical landscapes. We present two sub-themes describing (1) the personal and societal implications of the pandemic, and (2) navigating social support, public, and clinical landscapes.

#### 3.1.1. Personal and societal implications of the pandemic

Despite facing limitations to engage in formerly enjoyed activities, older cancer survivors regarded the pandemic as an opportunity to slow down and reflect on their lives; one participant described how she had taken some time to reflect on who she was, stating that she hadn't “*thought about that in a while*”. Another participant described the pandemic as another obstacle in his life that he had to overcome. He described that since he had ‘beaten’ cancer: “*I'll beat the pandemic, I'll beat anything*”. These reflections seemed most apparent after

**Table 1**  
The demographic and clinical characteristics of participants.

Demographic characteristics	N (%)	Clinical characteristics	N (%)
<b>Age (years)<sup>A</sup></b>	72.1 (5.8)	<b>Diagnosis</b>	
<b>Gender</b>		Breast cancer	15 (50.0)
Male	13 (43.3)	Colon or rectal cancer	15 (50.0)
Female	17 (56.7)	<b>Received chemotherapy<sup>B</sup></b>	
<b>Marital Status</b>		Yes	29 (96.7)
Married or common-law	23 (76.7)	No	0 (0)
Widowed	3 (10.0)	<b>Time (mos) since chemotherapy<sup>A</sup></b>	20.0 (13.4)
Separated or divorced	1 (3.3)	<b>Received radiation therapy<sup>B</sup></b>	
Single (never married)	3 (10.0)	Yes	17 (56.7)
<b>Parental status</b>		No	12 (40.0)
Have children	23 (76.7)	<b>Time (mos) since radiation therapy<sup>A</sup></b>	24.6 (12.8)
No children	7 (23.3)	<b>Received other cancer treatment<sup>B,C</sup></b>	
<b>Education</b>		Yes	9 (30.0)
Up to high school graduate	9 (30.0)	No	20 (66.7)
Up to post-secondary graduate	14 (46.7)	<b>Time (mos) since other treatment<sup>A</sup></b>	24.2 (13.5)
Up to graduate-level graduate	7 (23.3)	<b>Medication use<sup>B</sup></b>	
<b>Current work status</b>		Not taking medication	5 (16.7)
Retired/not working	28 (93.3)	For cancer only	6 (20.0)
Working at a job/business	2 (6.7)	For cancer and non-cancer	2 (6.7)
<b>Resides in</b>		For non-cancer only	16 (53.3)
Urban location	19 (63.3)		
Rural location	11 (36.7)		
<b>Ethnicity</b>			
Caucasian	28 (93.3)		
Non-Caucasian	2 (6.7)		
<b>Religious or spiritual</b>			
Yes	16 (53.3)		
No	14 (46.7)		

The bolded letters denote main content areas.

participants had taken initial actions to prepare for the pandemic (e.g., stocking up on groceries and supplies) although another participant – who described her cancer experiences as helpful for coping with the pandemic – was still unsure about how she could have prepared herself. She also believed that isolation for an extended duration might be problematic: “being isolated at home, I don’t think it’s a good idea in the long run”.

Older cancer survivors described how the pandemic posed challenges at the societal level. One participant expressed the pandemic as “another hurdle our society’s got to deal with”, whereas other participants felt the pandemic was a reminder of our interconnectedness through collective actions like social distancing and mask wearing. Another participant expanded this idea by the following comment: “I think the pandemic made me realize even more how much we need to depend on each other. Even just to stay at home. ... I think it’s for the greater good and I’m willing to make those sacrifices”. Nevertheless, the social implications of the pandemic were identified as particularly challenging, as clearly described by one participant: “if you’re an extremely social cat; that’s probably one of the toughest things of the pandemic and we may have to change our way of thinking as a society”.

### 3.2. Navigating social support, public, and clinical landscapes

Although social support from family and friends could be maintained somewhat during the pandemic using technology, some participants expressed a loss of support received from other cancer survivors and from other in-person social activities. While some participants would not use online formats to engage these supports, others

appreciated the serendipitous or informal connections they had established. For example, one participant continued to support patients with cancer who attended the cancer clinic during the pandemic by sewing masks that she donated to the clinic.

Participants were mostly agreeable to personal protective equipment (PPE) and physical distancing precautions to mitigate the spread of COVID-19 but described varying perspectives about their willingness to enter into public spaces and how to navigate changes to social interactions. One described entering the hospital to receive care: “the people involved have done everything possible to make it so that they’re not going to be allowing COVID to spread to their incoming patients. So I have not had any feelings of apprehension about getting into these hospital settings even though they claim the hospital is a great place to catch stuff”. However, other participants spoke of their enhanced risk for COVID-19, which was especially concerning when they were not able to physically distance in public; this concerned one participant so much that she did not attend her friend’s funeral and cancelled a vacation that she’d been looking forward to for a year. Still others expressed “little tricks” that they’d learned to live with PPE and physical distancing recommendations. For instance, when planning to go shopping, participants limited the number of times they went out, texted neighbours to see if they needed anything so as to reduce the number of trips out, went “off hours”, or, as described by one participant: “if you time it right, you don’t have to wait [in line]”.

### 3.3. Suggestions for future care delivery

Participants described the myriad ways that healthcare services had changed since the pandemic started. This was problematic for these older adults who were new cancer survivors because they were just starting to adapt to life beyond the cancer care system and to their post-cancer reality. Synthesizing their views, we identified four common recommendations within this theme: 1) enhanced baseline information; 2) facilitate caregiver support and engagement; 3) greater technology integration; and 4) sustained use and public appreciation of PPE (See Fig. 1).

#### 3.3.1. Enhanced baseline information

Participants valued the knowledge and expertise of their oncology team, but the sudden change in service provision left some participants feeling like they did not have adequate information or resources (e.g., written information, summaries of conversations from health care appointments, or education from allied professionals) to engage in survivorship self-care, now that health services had changed so drastically. One participant described: “Everything’s pretty well closed. Now it’s started to open up, but because it was closed for so long, it was a long time to get any help if there was any available. So I think that the pandemic made everything much worse than from before, and before it wasn’t much to start with. So you know you went from nothing to nothing. So it made it much more difficult, that’s for sure.” Additionally, participants desired provider recommended resources suitable to meet their needs and to receive written information about who to contact and when for both follow-up information, and if new symptoms occur. This material would be useful for participants to draw upon during the pandemic since they described finding reliable information as “difficult to get” and felt that “there’s no one [they could] count on to get any help”. Furthermore, these actions would permit cancer survivors to take reliable and individualized information to process on their own time resulting in greater education about their condition and how to manage it. These strategies would be useful for older cancer survivors, one of whom expressed concern about not being able to access care if it was needed. He said: “if something was to go wrong or I was to develop something that I felt needed attention, I’m not 100% confident that I’d be able to get it like I would’ve a year ago”.

#### 3.3.2. Facilitate caregiver support and engagement

Participants felt that creating opportunities for support persons to be involved in care was critically important. There was general agreement

# Older survivors of cancer & COVID-19: Recommendations to support coping

## RECOMMENDATIONS

- Written information summarizing survivorship visits
- Share visit information in multiple formats

## 1. Enhanced baseline information

Participants valued the expertise of their oncology teams' knowledge, but the sudden change in health services left them feeling unprepared. They felt more could be done to better prepare older survivors of cancer to engage, should there be interruptions in care.

## 2. Facilitate caregiver support & engagement

Changes in visitor policies were a huge concern for survivorship follow-up appointments. Creatively facilitating caregiver involvement was a critical point for older survivors of cancer.

## RECOMMENDATIONS

- Facilitate caregiver attendance via technology (even phone)
- Make peer supports/or social work presence standard care

## RECOMMENDATIONS

- Allow online/telephone group appointments between multiple specialties
- Use technology for booking appointments

## 3. Greater technology integration & support

Older survivors of cancer recognized the need to pivot to virtual and telephone visits but wanted more support to engage in such measures and felt technology could be used more for some things, and less for others.

## 4. Sustained use and public appreciation of PPE

Participants valued expanded use of masks and PPE and felt the pandemic might increase awareness of the need for masking and PPE use to protect those vulnerable to common illnesses like cold and flu, even after the current pandemic.

## RECOMMENDATIONS

- Encourage sustained mask used for those with cold/flu symptoms even in non-pandemic times

Fig. 1. Summary of participant recommendations.

among participants that support persons should be at all appointments and that greater awareness about available peer supports would be useful to support coping with cancer-related concerns, during the pandemic. For some participants, the critical changes in visitor policies that prohibited support persons attending clinic appointments was very concerning. Participants made suggestions, one of which was to simply offer phone-conferencing to allow caregivers to be present at appointments. One older adult and his caregiver described how they asked the oncologist if the caregiver could join the appointment via phone, from the parking lot, in the absence of coming in person: *“I asked if I can be put on speakerphone and the three of us could talk together. And he said, “Go right ahead. Be my guest”.* This small gesture had a significant impact on the caregiver's ability to support the survivor, leading them to suggest it be offered to all older adults in a similar position.

### 3.3.3. Greater technology integration and support

Health care delays and withdrawal of supportive and rehabilitative care resources due to the pandemic were a concern for many participants that left them feeling as though they *“were going backwards”* in their cancer recovery. One participant described the negative impact of not being able to access needed resources during the pandemic: *“Before the pandemic, I would do a lot of activities and exercise - because that really helps me with the condition. ... While I was exercising, I was doing quite well, but ... because I'm not able to go to the gym anymore causes my condition to worsen. So that has had a huge effect on me”.* As a result, older adults made suggestions about how technology might be used to facilitate ongoing participation in such activities which promote health and wellbeing. Participants also suggested the need for online or telephone group appointments between multiple specialties and/or caregivers, and greater use of telephone wellness follow-ups. One participant believed that such actions would *“make things a lot more efficient”* for both patients and healthcare professionals. However, older adults were cautious about over-committing to the use of technology as they felt something was missing and wanted the social interaction of in-person visits - which they preferred. One woman put it simply: *“This being handled over the phone is a little unnerving. I would much rather be face-to-face”.* Despite misgivings, older cancer survivors remained receptive to using technology if it would minimize delays to their cancer screening and follow-up schedule, so long as it was adequately introduced and supported.

### 3.3.4. Sustained use and public appreciation of PPE

Participants had insightful comments about the use of PPE and physical distancing. Some participants believed that PPE and physical distancing *“should become habitual after [COVID-19]”* in that *“precautions like masks [and] social distancing will help even in the common flu”.* This was especially important to many participants who described themselves as ‘early adopters’ given their double vulnerability as older adults who had cancer. Participants also described that they had worn masks during their cancer treatment, and appreciated that there was a culture change around the use of masks for people feeling unwell, which could be helpful to protect cancer survivors and people on treatment even when not in a pandemic.

## 4. Discussion

Through this study we gained a greater understanding about older cancer survivors' reflections of the COVID-19 pandemic and their suggestions for future care delivery. Participants described their reflections about the pandemic, including the challenges and learned/potential strategies for mitigation of COVID-19, on both individual and societal levels. Through these reflections, older cancer survivors provided suggestions about how future care could be delivered, both during the pandemic and beyond. These suggestions may promote older adults' engagement in their post-treatment cancer journey.

Participants felt strongly that they be provided with more information when being discharged from their oncology team, including

written records of their clinic visits, which is in alignment with the requests of older cancer survivors in other research [31]. Although a treatment summary is recommended for cancer survivors who are completing treatment [32,33], providing this information at each health care appointment provides older adults with individualized information to process on their own time and share with others in their personal networks (e.g., family, friends, or health care professionals). This measure is even more important when support people cannot attend appointments. Furthermore, such information should be provided in a manner that suits the abilities of the person (e.g., large font, hard- vs electronic documents, etc. [32]). Sharing geriatric assessment summaries from clinic visits has been found to increase patient and caregiver-centered communication [34]; our study findings seem to indicate a critical sustained need for sharing of clinic visit summaries into survivorship for older adults. Additionally, creatively permitting caregivers or support persons to attend and actively contribute to discussions with the cancer care team can relieve cancer survivors' concerns about not hearing all shared information or not asking desired questions of professionals during discussions.

Preparing older adults for what to expect after treatment by engaging principles of self-management [35] is particularly useful, in the event that usual resources become unavailable (e.g., due to a pandemic or across geographical settings (e.g., rurality). Indeed, many older adults mentioned the importance of being given more options for information and support, given the pandemic-imposed move to virtual care. These perspectives seem to signal the importance of engaging patients in self-management discussions early in the cancer trajectory and throughout survivorship [15]. The need to enhance technological comfort, specifically among those over 75 years of age [36] has been discussed elsewhere as a critical aspect of engaging older adults in self-management. Adopting a self-management approach may further prepare older adults and their caregivers to engage with care when only virtual **options** is possible, in light of the hesitancy described by some participants. In this way, technology could be used in a variety of capacities, such as appointment scheduling, well-visit follow ups, or supporting older adults as they find information that is reputable and relevant to their situation.

Although these older adults desired greater amounts of information and were open to using technology to achieve this, it is important to consider how this might impact social isolation among older cancer survivors. However, varying technologies offer different possibilities to reduce social isolation among older adults [37,38] and so social isolation, and the role of technology, remains an area for further research among older cancer survivors [39,40]. While a variety of interventions have been explored in this regard [41], early assessment and prevention of social isolation within this population is paramount [42,43].

### 4.1. Limitations

Given that this is a qualitative study, the goal was not to generalize the results but to gain a deeper understanding about older adult cancer survivors' reflections of the pandemic and recommendations for care. Given the sample size and the homogeneity of participant demographics (e.g., ethnicity, education, and income) results should be interpreted as an addition to the scant knowledge base around cancer survivorship in the pandemic.

## 5. Conclusion

As identified in the International Society for Geriatric Oncology Guidelines on adapting care for older adults with cancer in COVID-19, little is known about the survivorship experiences of older adults with cancer during the pandemic [10]. Older adult cancer survivors who participated in this study reflected on the pandemic with general acceptance about the required personal and societal changes. While older cancer survivors appreciate the need for healthcare services and

societies to rapidly transform, they offered suggestions as to how they could be supported in spite of these changes. Capitalizing on their suggestions to enhance baseline information, facilitate caregiver support, enhance support for the use of technology, and consider sustained use of PPE, while drawing on the numerous strengths of older cancer survivors, may enhance older adult survivors' ability to cope with their cancer-related concerns. Future research will focus on working with stakeholders to understand how to implement these recommendations into cancer survivorship care for older adults.

### Author Contributors

Conceptualization: JG, KH, DK, SM, CB, RK, MB. Data curation: JG, KH. Formal Analysis, Methodology: JG, KH, JG, KH. Funding acquisition: JG, KH, DK, SM, CB, RK, MB. Statistical analysis: JG. Writing- original draft: JG, KH. Writing- review and editing: JG, KH, DK, SM, CB, RK, MB.

### 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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### Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.jgo.2020.11.009>.

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