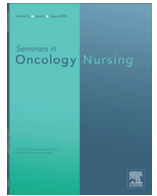




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The Needs of Older Adult Cancer Survivors During COVID-19: Implications for Oncology Nursing

Heather M. Kilgour^a, Jacqueline Galica^b, John L. Oliffe^{a,c}, Kristen R. Haase^{a,*}

^a School of Nursing, University of British Columbia, Vancouver, BC, Canada

^b School of Nursing, Queens University, Kingston, ON, Canada

^c Department of Nursing, University of Melbourne, Carlton, VIC, Australia

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ABSTRACT

Objectives: Older adults living with cancer have been described as more susceptible to coronavirus disease 2019 (COVID-19) and in need of special attention during the COVID-19 pandemic. For cancer survivors, the first year post-treatment is a critical time because many individuals transition back to their primary care provider and adjust to physical and psychosocial changes that occurred during their cancer treatment. In this longitudinal qualitative study, we followed a cohort of older adult cancer survivors through the first three waves of the pandemic to describe their experiences as a means for providing recommendations for how oncology nurses can tailor support to this unique population.

Data Sources: We conducted individual, semi-structured qualitative interviews with 24 older adults at three time points during the pandemic. Data were analyzed drawing from interpretive descriptive methodologies.

Conclusion: Older adult cancer survivors' needs shifted during the pandemic from feeling confident and self-assured during the early days of COVID-19 to growing uncertainty and unease about their health and well-being. The main survivorship concerns included a preference for in-person appointments (as opposed to virtual), barriers to caregiver attendance at appointments, and diminished access to health care services.

Implications for Nursing Practice: Oncology nurses play a critical role providing care to older adult cancer survivors and are most familiar with unique patient needs and the gaps in services they face. We provide recommendations for oncology nursing practice that consider the shifting needs of older adult cancer survivors during COVID-19 and beyond.

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Background

The COVID-19 pandemic has had a profound and sustained impact on health care systems globally. Older adult cancer survivors are at increased risk of coronavirus disease 2019 (COVID-19) due to their immunocompromised status and advanced age.^{1–5} Emerging evidence has demonstrated an increase in negative outcomes of COVID-19 for older adults with cancer, including hospitalization, intubation, admission to the intensive care unit,^{1,3,4} and increased mortality.^{1,2}

As older adults with cancer transition to survivorship, they face a number of challenges, including physical, emotional, practical, and health-related changes.⁶ Numerous unmet needs have been identified, including the need for ongoing dialogue with health care providers, access to survivorship services, and assistance with managing long-term cancer treatment side effects.⁷ This period of transition has been further complicated by COVID-19 and its impact on health

care systems and services. As cancer survivors navigate their post-treatment changes, they are concurrently facing adjustments to survivorship plans, the health risks of the pandemic, and the accompanying lockdowns and social distancing practices.⁸ As the pandemic continues, disruptions in oncology care have emerged, including a shift to virtual appointments, delays in tests and surveillance scans, and the postponement of treatments or surgeries.^{3,9} Previously identified survivorship concerns have been amplified during the pandemic, including fear of recurrence, anxiety, depression, and loneliness.^{8,10} The impact of COVID-19 on mental health-related survivorship concerns warrants further exploration, particularly given the diminished access to mental health resources and geriatric assessment amid the COVID-19 pandemic.¹¹ As the pandemic persists, it is important to understand the emerging needs of older adults as they transition to the post-treatment phase of cancer survivorship and to explore the nursing role in supporting older adults during the pandemic.

Nurses have played, and continue to play, a critical role in the COVID-19 pandemic.¹² The ubiquity of nursing roles across health care settings makes us ideally placed to provide information and care

* Address correspondence to: Kristen Haase, Assistant Professor, Faculty of Applied Science, School of Nursing, University of British Columbia, Vancouver Campus, T201-2211 Wesbrook Mall, Vancouver, BC, V6T 2B5 Canada.
E-mail address: kristen.haase@ubc.ca (K.R. Haase).

TABLE 1
Cancer and Health-Service-Delivery-Related Questions from Interview Guides

Time	Example Interview Questions
Interview 1 (July/August 2020)	<i>What's it been like to be an older cancer survivor—someone who has completed treatment for cancer—in this pandemic?</i> <i>How do you think you're doing with coping with your cancer-related concerns during the pandemic?</i> <i>Of the changes that you've gone through as an older cancer survivor during this pandemic, what stands out to you as the most important?</i>
Interview 2 (January/ February 2021)	<i>In your first interview in the summer, we talked about cancer-related coping during the pandemic. Can you describe any changes you may have experienced since then?</i> <i>Have you had any major cancer-related concerns since our last interview?</i> <i>Have there been challenges related to getting or taking medications or your ability to attend clinics?</i> <i>What are your thoughts about managing your cancer-related concerns going forward in the pandemic?</i>
Interview 3 (March 2021)	Older adults were provided with key findings from interviews 1 and 2: <i>Older adults told us they were concerned that (a) their caregivers could not go with them to in-person appointments, (b) they had less support managing survivorship concerns, and (c) that their cancer might recur. They had mixed opinions about virtual appointments. Some liked not having to travel to in-person appointments in winter.</i> We then asked reflective questions: <i>What do you think of these findings?</i> <i>What doesn't make sense/resonate with you?</i> <i>Which of these findings resonates most with you?</i>

regarding virus containment, mitigation strategies, and treatments. Oncology nurses provide a critical and adaptive role in the pandemic supporting patients with cancer through evolving uncertainties.¹³ Indeed, nurses deliver essential symptom assessment, psychological support, patient education, and patient advocacy.^{14–17} A recent collaborative position statement from international oncology nursing groups¹⁸ highlights the unique needs of older adults with cancer, emphasizing the importance of specialized oncology nursing care for this patient population. The position statement¹⁸ recognizes the role of oncology nurses in advocating for the specific needs of older adults with cancer, providing patient and family-member education, recognizing age-related issues, and supporting older adults during and after their cancer treatments.¹⁸ Oncology nurses are well-positioned to use these skills to address the needs of older adult cancer survivors as they transition to a post-treatment life during the pandemic. In this article, we explore the unmet needs of older adult cancer survivors and discuss implications for oncology nursing practice.

Objectives

In this longitudinal qualitative study, we followed a cohort of older (>60 years) adult cancer survivors through three waves of the pandemic (July/August 2020, January/February 2021, and March 2021). In this article, we describe the shifting needs of older adult cancer survivors across the pandemic and provide recommendations for how oncology nurses can tailor nursing care and support to this unique population.

Methods

We conducted an interpretive descriptive¹⁹ longitudinal qualitative study with a Canadian sample of older adult cancer survivors. An interpretive descriptive approach is congruent with the approach of our research team, which brings together oncology research experience grounded in clinical nursing and is practically oriented to the needs of older adult cancer survivors and the implications for nursing care. Through the present analysis, we sought to understand the needs and experiences of older adult cancer survivors across COVID-19 and ground these findings in oncology nursing practice, consistent with an interpretive descriptive approach.¹⁹

Sample, Setting, and Procedures

Following ethics approval (H20-03822), we recruited individuals recently discharged from the Cancer Centre of Southeastern Ontario in Kingston, Ontario, Canada, through a research database, a process

described elsewhere.²⁰ In Southeastern Ontario, a lockdown occurred in March 2020, during which in-person health care appointments ceased and public health safety measures were implemented. Three authors (JG, HK, KH) completed telephone interviews with participants at three time points during the pandemic. Interviews lasted approximately 45 minutes, were audio recorded, and transcribed verbatim by a professional transcription agency. The first round of interviews took place in July and August 2020, or wave one of the pandemic. The second round of interviews took place during January and February of 2021, and the final set of interviews took place during March 2021. During the third interview, we used an infographic of the preliminary study findings created with the assistance of a plain language editor. We used the infographic to discuss our interpretation of results from the first two data collection time points and elicit further perspectives. Interview questions touched on a range of topics, including cancer-related concerns, coping, health challenges, and changes to health care appointment delivery. In this article, we focus on the cancer and health service delivery-related data and findings (see Table 1 for example questions across the three interviews).

Analysis

We used an interpretive thematic analysis approach, looking for patterns and meanings in the data.^{19,21} Data was organized using NVivo 1.3 software. Two authors (HK, KH) engaged in the data analysis process, working together on analysis by first reading and re-reading the transcripts and then inductively deriving a coding structure. Once we agreed on the overall structure and labels of the codes, we collectively coded the remaining transcripts using this coding structure. We discussed the emerging coding structure with the team and, leading up to the third set of interviews, met as a team to discuss the preliminary themes to date and define additional areas to probe in the final interviews. The analyses continued across the three data collection time points with the goal of distilling what prevailed as participant experiences and accounting for variations on those predominant perspectives. We presented our study findings at virtual supportive care rounds at a local cancer center to get feedback and consult stakeholders (oncologists, oncology nurses, patients, etc.) regarding the interpretation and clinical relevance. This final step is congruent with an interpretive descriptive approach by ensuring that findings are practical and have clinical relevance.¹⁹

Rigor

We used several strategies to ensure our study was conducted rigorously and aligned with an interpretive descriptive approach.¹⁹ We

sought epistemological integrity and analytic logic through coherence in the research questions, methods, and analyses. We involved team members at multiple points in the analysis and shared our preliminary findings with participants and stakeholders to achieve interpretive authority. Finally, we limited our claims and interpretations to the data we collected and noted the strengths and limitations of such methods in the limitations section.

Findings

Older adult cancer survivors participated in this study at three time points during the pandemic: during wave one ($n=24$), wave two ($n=18$), and prior to vaccination/wave three ($n=18$). Six participants were lost to follow-up after wave one. Information within this paragraph describes the demographic and clinical information of participants who completed the first interview. Ages ranged from 63 to 83 years old (mean = 71.5; standard deviation = 5.7) with slightly more participants who identified as female ($n=14$, 58.3%) participants. All participants had been discharged from cancer care within the last 12 months and had been diagnosed with breast ($n=12$, 50%) or colorectal cancer ($n=12$, 50%). All participants had received their last treatment 1–41 months prior to interview one, with a mean time since last treatment of 19.4 months ($SD=10.1$). Most participants had received chemotherapy ($n=23$, 95.8%), and some received radiation ($n=13$, 54.1%) or other cancer treatments ($n=6$, 25%) such as targeted therapy, immunotherapy, or surgery. Further demographic and clinical information are provided in Table 2.

Across the pandemic, older adult cancer survivor's needs evolved from remaining positive and connected to increasing distress related to the persistence of the pandemic. Colder weather, shorter days, and increased restrictions contributed to feelings of isolation, impacting older adult's well-being. Throughout the interviews, we noted survivorship concerns related to virtual appointments, caregiver support, and a pressure to stay healthy given the restraints on health care services. We organized these concerns into the following themes: (1) Concerns about virtual versus in-person appointments; (2) Barriers to caregiver attendance at appointments; and (3) Impediments to accessing health care services.

TABLE 2
Demographic and Clinical Information

	Interview 1 ($n=24$)	Interview 2 and 3 ($n=18$)
Age	71.5 (5.7)	71.1 (4.9)
Gender		
Female	14 (58.3%)	12 (66.7%)
Male	10 (41.7%)	6 (33.3%)
Marital Status		
Married or common-law	18 (75%)	15 (83.3%)
Widowed	2 (8.3%)	0 (0%)
Separated or divorced	1 (4.2%)	1 (5.6%)
Single (never married)	3 (12.5%)	2 (11.1%)
Education		
Up to high school graduate	5 (20.8%)	2 (11.1%)
Up to postsecondary graduate	13 (54.2%)	11 (61.1%)
Up to graduate-level graduate	6 (25%)	5 (27.8%)
Ethnicity		
White	22 (91.7%)	18 (100%)
Black	1 (4.2%)	0 (0%)
Indigenous	1 (4.2%)	0 (0%)
Cancer diagnosis		
Breast cancer	12 (50%)	11 (61.1%)
Colon or rectal cancer	12 (50%)	7 (38.9%)
Cancer treatment		
Radiation	13 (54.1%)	13 (72.2%)
Chemotherapy	23 (95.8%)	17 (94.4%)
Other	6 (25%)	6 (33.3%)
Time since last treatment (months)	19.4 (10.1)	19.4 (11.0)

Concerns About Virtual Versus In-Person Appointments

Throughout the pandemic, there was a shift from in-person to virtual or telephone appointments. In the region where this study took place, in-person appointments ceased during the initial lockdown in March 2020, as noted in the methods section. Although older adults described understanding why this transition occurred (ie, reduce risk of COVID-19 exposure), many expressed a preference for in-person appointments. Participants described in-person appointments as more comforting when compared to virtual appointments. One participant explained: "It's just reassuring to see them in person, to see their face, to watch their non-verbal. You know what I mean? It's just nicer." Beyond the nonverbal cues of their physician or nurses, older adults described the importance of their health care team being able to examine them and note any physical changes. One participant shared a story describing how prior to the pandemic her oncologist was able to see her in person, identify that she was unwell through visualizing physical changes, and send her for follow-up tests. This participant worried her complication may have gone undiagnosed if the appointment was virtual, explaining, "There [was] something wrong and she [oncologist] knew right away that there was a problem. But had that been a phone-call, I don't think she'd have ever diagnosed it."

Older adults described barriers to virtual appointments, including difficulty hearing over the phone, appointments feeling more abrupt or rushed, and feeling less connected to their health care team. One participant explained that their virtual appointments tended to be with residents or medical students, stating, "I've had three appointments in the pandemic, and I haven't spoken to my actual staff person yet." There was concern that telephone appointments (which were the predominant method of virtual consult) did not allow the clinician to fully see the patient.

Older adult cancer survivors noted some benefits to virtual appointments, describing less time spent in waiting rooms and time saved by not having to travel. Despite this, most participants described their continued preference for in-person appointments. For example, one participant shared, "Well, all my appointments were across the phone. . . I don't think they're as good as the in-person ones. I guess it saved us a lot of trips because . . . well, if I go to appointments, half a day is shot by the time we drive there and back, . . . but I would sooner have the in-person appointments when you're only having them every six months or so anyways." As the pandemic wore on, we noted that in subsequent interviews with participants, there was growing reluctance about virtual care. Many participants had put off appointments hoping they would be able to attend in-person; however, with the continued lockdowns they were still unable to see their clinician in person.

Barriers to Caregiver Attendance at Appointments

As strict visitation restrictions remained throughout the pandemic, many participants expressed concern that family members or friends were not able to attend appointments. This concern was multifaceted, affecting not only the nature of their appointments but also creating worry for their family members waiting outside the cancer center. One participant described how their spouse had to wait 3 1/2 hours in a cold car during one of their appointments (in the middle of a Canadian winter). Another discussed how they worried about their partner not having access to a restroom while they were waiting outside the cancer center. When discussing the main change to health care during the COVID-19 pandemic, this same participant shared, "Well, the main difference, the main problem is the fact that she can't come in with me," explaining, "we do everything together."

Participants discussed how attending appointments alone resulted in them having less access to information about their treatment plan. This was in part due to having only one set of ears listening to information shared during the appointment and in part due to not having as many people to ask questions of clinicians. One older

adult elaborated on the importance of having a loved one there to listen, stating *"It's so good to have that extra pair of ears to, you know, come home and discuss it with your partner or spouse and say this is what I heard, and they'll say, 'no, no, no, that's not what . . . she said at all.' . . . So, I think it's really important that when people get back on track that they are allowed to take a person with them to appointments, because it's so, so beneficial."* A second participant shared the importance of having their partner in attendance, explaining, *"I'm finding that my memory is poorer, and I don't always think of things. So, with [partner's name] comments, they're very pertinent."*

As the pandemic persisted and the accompanying visitation restrictions remained, strategies to overcome attending appointments alone were explored. One participant described how they had initially attempted to record their appointments with their oncologist, however, noted this was challenging and that they *"haven't been doing that lately."* One participant found a successful strategy, explaining *"what I started to do was I made a list of questions myself. So, when I went in . . . I didn't forget any questions I would jot down the answers. So, when I couldn't take anything that was fine."*

Impediments to Accessing Health Care Services

Older adult cancer survivors expressed concern over access to health services during the COVID-19 pandemic. This included both cancer services and other health-related services. One participant described how they had hired a caregiver to come into their home prior to the pandemic; however, the caregiver resigned due to fear of contracting COVID-19. When asked about their biggest concern moving forward, this participant described how they worried that the persistence of the pandemic was going to make getting home help more difficult. Another older adult worried about services closing and asked her physician if their office would be closing upon hearing that the local hospital was admitting COVID-19 patients.

Many participants described delays to their cancer care follow-up visits, including deferred appointments and scans. One participant explained, *"It's a little disappointing because the COVID-19 has really backed up any type of appointment you can get. And you know it's gone from a couple weeks to three or four months for things."* This created confusion for some participants regarding their survivorship care plan. After sharing that their appointments have *"been put on hold since the pandemic,"* one participant explained, *"They want you to do these follow-up check-ups, but you can't get in [to see them]."*

Older adults expressed a desire to 'stay healthy' so as not to place additional pressure on the health care system. One participant felt this was their moral duty, expressing *"with the systems and the pressure on the system right now, I want to do everything I can to stay as healthy as I can. Mentally and physically."* They went on to say, *"The whole social structure is under pressure, so the less you have to rely on other people or other services the better off you'll be, I think."* Some participants described avoiding accessing services throughout the pandemic. One such participant stated, *"You don't really want to be bothersome with what's relatively minor compared to what they're really dealing with."* A second participant described that because health care providers *"don't want you in there,"* they had been spending more time searching the Internet and 'googling' health concerns and attempting not to call. Another participant shared they have been putting off discussing a medication concern with their oncologist throughout the pandemic so as not to be bothersome.

When asked about their biggest fears moving forward, many participants expressed fears about cancer recurrence. Some participants felt their fear of recurrence was independent of the pandemic. One participant explained, *"I don't think it had anything to do with the pandemic. To me it's irrelevant. You know? Just a fear that you have of the results—and no matter what's going on in the world."* Others described concerns over recurrence amidst the pandemic and worried what that might mean for health care supports. One participant explained,

"It's lasting longer, and I always think if the cancer's going to come back it's probably not going to be the first six months, right? It'll be you know, maybe a year, year into it you know, and so maybe as it gets longer—or if COVID goes longer I may have more concerns about cancer recurrence and the support." And still others described worry that treatment may look different during the pandemic or that older adults with cancer may not be prioritized. One participant stated, *"If there is a complication or say the cancer resurfaces, will treatment and access to facilities be available? And we all know the pressure that's being put on hospitals and ICUs and surgeries. And they mentioned cancer surgeries that are being put on the back burner or cancelled until further notice. So, if it comes up again, it might be a lot different than the first time."*

Discussion

In this article, we explored older adult cancer survivor's cancer-related needs across three time points during the COVID-19 pandemic. Our key findings relate to the impact of virtual appointments, barriers to caregiver attendance at appointments, and impediments to accessing health care services across the pandemic. Although research preceding the pandemic describes the concerns of older adults related to virtual care^{22,23} and access to health services,²⁴⁻²⁶ our findings highlight these amplified concerns during the pandemic.

Within our study, older adults described that the majority of survivorship appointments have been conducted virtually during the pandemic. This trend has been documented globally,^{27,28} with a recent Canadian study reporting an increase in virtual appointments from 1.6% pre-pandemic to 70.6% during the pandemic.²⁹ This study further describes that older adults increased their virtual care use at similar rates as other age groups (eg, young adults).²⁹ Despite the frequency of virtual appointments, participants in the current study expressed a strong preference for in-person appointments. Indeed, participants shared what they perceived as barriers to virtual appointments including difficulty hearing, appointments feeling rushed and less reassuring, and concerns over health care providers not physically seeing and examining them. As the rapid transition to telehealth occurred, little attention was paid to supporting older adults in this abrupt transition, despite their distinct 'double vulnerability.' A recent study exploring technology use in older adults during the pandemic described barriers such as lack of access to technology, lack of interest, and physical barriers caused by chronic disease or illness.³⁰ As recommendations to maintain virtual health care post-pandemic emerge, and older adults are forced to embrace technology, considerations to support older adults during this must be thoughtfully considered. Our study findings lend important information to older adult challenges for virtual appointments and highlight opportunities to optimize the experiences of older adults using telehealth services beyond the pandemic to ensure that they are not 'left behind' in the move to virtual care. Moreover, given the preference for in-person consultations among participants in the current study, cautions emerge to ensure budget efficiencies and convenience do not drive virtual appointments to entirely erode in-person options.

Across the pandemic, participants described concerns related to caregivers being unable to attend in-person appointments. The main concerns included less access to information during appointments without a support person present to both listen to the health care team and to ask questions. Furthermore, some participants referenced difficulty with memory, hearing, and cognition when describing the importance of having caregivers in attendance. This may have important implications because older adults may not have access to the same information as when their caregiver was in attendance. Caregivers play an important role in providing emotional support to patients, assisting with activities of daily living and advocating on behalf of their loved ones.^{31,32} If caregivers are unable to attend appointments, this important role may be diminished, preventing patient advocacy and access to information. As our findings suggest,

consideration must be made to involve caregivers in cancer survivor follow-up appointments whether virtual or in-person. In particular, patients should be encouraged to include a partner or friend in virtual consults to reduce these barriers to care.

Participants described a pressure to stay healthy during the pandemic, so as not to burden the health care system. Older adults discussed how they were putting off discussing health care concerns with their oncologist and were attempting to manage concerns independently through means such as googling health care concerns. This has important implications for cancer care moving forward as there may be suboptimal outcomes for cancer survivors due to delaying or concealing concerns during the pandemic. Delays in cancer screening, oncology visits, treatments, and surgeries have already been reported in the pandemic literature across the cancer continuum.^{33,34} Ensuring cancer survivors have adequate opportunities to bring survivorship concerns forward must be a priority of health care providers. Furthermore, nurses must support effective self-management strategies through a collaborative care model to avoid older adults self-triaging out of the supports they need.

Within our study, participants described an amplified fear of recurrence during the COVID-19 pandemic. Older adults described concern that cancer care would not be prioritized and worried that services would be unavailable during the pandemic. This fear of recurrence is consistent with other COVID-19-related research in cancer survivors.^{8,10} This is particularly concerning given the lack of access to health-care-related resources during the pandemic, particularly mental health services.¹¹ Oncology nurses are ideally positioned to address these increased fears and provide support to older adults during this challenging time. In particular, self-management skills and mindfulness should be taught routinely to reduce patient anxiety and promote self-health.

Limitations

There are several limitations to this study alongside notable strengths. First, mostly Caucasian and well-educated older adults participated in this study, which limits the diversity of perspectives represented in our findings. Second, interviews were conducted via telephone, and therefore, we were unable to capture visual cues, facial expressions, and body language. An important strength of our study is the repeated engagement with participants, which allowed us to develop rapport with participants, enabling older adults to share their experiences openly, and for us to understand what prevailed as their experiences and challenges over time.

Implications for Nursing Practice

Oncology nurses play a critical role in caring for older adults with cancer, highlighted by a recent position statement on the need to optimize oncology nursing to address barriers to care.³⁵ Understanding the cancer-related needs of older adult cancer survivors is an important step to providing tailored nursing care in the COVID-19 pandemic context and beyond.

Throughout the pandemic, many health care services have shifted toward a virtual format. Older adult cancer survivors have been clear: They have a preference for in-person appointments. Going forward, oncology nurses should consider patient preference and discuss with patients what would work best for them while ensuring public health guidelines are followed. Should virtual medicine grow exponentially postpandemic, oncology nurses can support older adults during this transition toward virtual health care. As is described in a recent position statement on care of older adults with cancer,¹⁸ nurses can assess the unique patient challenges to engaging with technology and act as a resource to support patients through this challenging transition. Additionally, nursing informatics may take a lead in this transition, ensuring the useability and acceptability of these virtual formats.

Older adults also noted a number of challenges to attending appointments alone, including having less access to information and diminished support to ask questions during appointments. Nurses can emphasize caregiver and family involvement during appointments should this be the patient's wish. Strategies to overcome these barriers may include phoning family members during in-person appointments, providing family members with written information, or encouraging family members to write a list of questions for the patient to bring. These strategies could become a regular part of appointments given that caregivers of older adults may also be older and experience similar barriers.

Conclusion

The purpose of this article was to explore older adult cancer survivor's health-care-related concerns throughout the COVID-19 pandemic. Older adult cancer survivors discussed their experiences with virtual appointments and expressed a preference for in-person appointments. Participants understood why caregivers could not attend appointments; however, they also discussed the resultant barriers such as accessing information. Older adults described a pressure to stay healthy throughout the pandemic and disclosed avoiding seeing their health care provider so as not to burden the health care system. Our findings provide important insight to the unmet needs of older adult cancer survivors during the pandemic. Knowledge of these unmet needs can guide oncology nurses as they provide support to this patient population. Future research should explore specific strategies for nurses to support older adults in the transition to virtual health care.

Author Contributions

Conceptualization: KH, JG; Funding Acquisition: KH, JG; Methodology: KH, JG; Data Curation: HK, KH, JG; Analysis: HK, KH, JG, JO; Writing – Original Draft: HK, KH; Writing – Review & Editing: HK, KH, JG, JO.

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Competing Interests Statement

The authors disclose that they have no known competing financial interests or personal relationships that could have influenced the work reported in this article.

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