



Unique needs of childhood cancer survivors during the COVID-19 pandemic

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Coronavirus disease 2019 (COVID-19) caused by the severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) is a global health pandemic that has caused significant morbidity and mortality for individuals worldwide [1]. Survivors of childhood cancer (CCS) may be especially vulnerable to both the physical and mental health impacts of COVID-19. Despite publications highlighting the unique risks for survivors of cancer amid COVID-19 [2, 3], little attention has focused on the specific needs of CCS. The aim of this commentary, therefore, is to highlight the unique physical and mental health needs of CCS to better inform healthcare professionals (HCPs) that may encounter CCS during the pandemic.

The survival rate for pediatric cancer has increased by more than 30% over the last several decades, resulting in exponential growth in the number of survivors. Currently, an estimated 500,000 CCS live in North America. Although these numbers are encouraging, CCS are at risk of experiencing significant late effects, defined as health problems that occur months or years after completion of cancer therapy caused by the cancer itself or the cancer treatment (i.e., chemotherapy, radiation, surgery, or hematopoietic stem cell transplant). Common late effects among CCS may include cardiac [4, 5] and pulmonary changes [5, 6], obesity-related health problems and endocrine dysfunction [7–9], and secondary malignant neoplasms [10]. Depression, anxiety, and post-traumatic stress [11] are also common. Ninety-five percent of CCS will be diagnosed with a chronic health condition by the age of 45; 80.5% will be diagnosed with a disabling or life-threatening condition [12].

Many of these late effects have severe consequences that can lead to premature mortality [13].

As part of their treatment protocols, CCS are typically treated with regimens including cytotoxic chemotherapies causing immunosuppression, potentially leaving them vulnerable to COVID-19. Certainly, emerging studies have shown that cancer patients on current treatment can be at high risk of severe or fatal COVID-19 [14, 15] and that long-term survivors of hematological cancers appear especially vulnerable [16]. The long-term implications of immunosuppressive therapies and their interactions with COVID-19 have yet to be discerned. In addition, health conditions that have been linked to a more severe course of COVID-19 including cardiac issues, pulmonary disorders, obesity, and diabetes [17] are common late effects among CCS. However, while it is likely that some CCS may be at risk of a severe course of COVID-19, many CCS may not be at greater risk and may be modifying their lifestyles and behaviors unnecessarily.

Among CCS, only 35% recognize that they are at risk for serious health problems due to their past cancer diagnosis and treatments, [18] setting them apart from survivors of adult malignancies. For example, CCS may not know which treatments they received, particularly those who are many years from treatment completion or were treated at smaller centers where survivorship care may be limited or absent. A lack of knowledge about their specific treatment history and potential risks for late effects would make it exceptionally difficult for CCS to interpret potential risks in the face of COVID-19. In addition to survivors themselves being unaware, it can be difficult for HCPs to interpret the risk of late effects. CCS encompass a heterogeneous population of patients. Therapeutic protocols and attendant toxicities have changed significantly over time. The toxicities of newer treatment protocols may still be unknown.

The significant uncertainty that surrounds COVID-19 is heightened among CCS and may lead to significant mental health consequences. In fact, preliminary data from our team [19] suggests that 73.7% of CCS feel they are at higher risk of

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experiencing severe complications of COVID-19. Yet, only 15.8% have reported receiving information about their potential risks. This information gap may lead to worsened mental health among CCS. Specifically, 42.1% of CCS reported their current mental health to be worse than before the pandemic. Examination of scores on standardized measures of mental health reveals that among our preliminary sample ($n = 120$), CCS scored above the clinical cutoff for anxiety (81%), depression (59.6%), and post-traumatic stress (21.1%). When asked to identify factors related to worsened mental health, CCS cited uncertainty related to how COVID-19 may impact them (47.4%), worries about contracting COVID-19 (54.4%), and concerns about how their past cancer and treatment may interact with COVID-19 (54.4%).

CCS may also be experiencing increased anxiety, or symptoms of post-traumatic stress due to reminders of their past cancer treatment amid public health recommendations to self-isolate, wash hands, and remain vigilant about symptoms of sickness. In addition, for those survivors who do attend follow-up care, anxiety may be heightened due to survivorship clinics closing altogether, or the postponing, canceling, or changes to regular follow-up appointments. Finally, as CCS are already at risk of social difficulties [11, 20], recommendations for social isolation may perpetuate feelings of loneliness. Amid the COVID-19 pandemic, therefore, the mental health of CCS may be significantly compromised.

Acknowledging the physical and mental health risks unique to CCS, some of the foremost pediatric oncology organizations have published guidelines for CCS amid COVID-19 including the Children's Oncology Group (COG) (<http://www.survivorshipguidelines.org/>), the International Guideline Harmonization Group (IGHG) (<https://www.ighg.org/ighg-statement-covid-19/>), and the Children's Cancer and Leukemia Group (CCLG) (<https://www.cclg.org.uk/coronavirus-advice/survivors>). However, as our preliminary data shows, this information is not adequately reaching CCS. Moreover, as such guidelines are often designed for medical professionals and not directly communicated to CCS, this has created an information gap which urgently needs to be filled.

In summary, we urge HCPs to be aware that CCS have specific and distinct needs amid the COVID-19 pandemic which are likely to differ substantially from survivors of adult cancer. Importantly, given the incredibly heterogeneous population of CCS, these needs are likely to be quite varied. The potential for unmet needs amid COVID-19 is compounded by the already substantial gaps in engagement and provision of follow-up. Even CCS who are normally engaged with follow-up care may not have had contact with their HCPs during the pandemic. Therefore, we must escalate efforts to communicate to CCS about the risks COVID-19 presents to them, both now and as new research is published. This will empower CCS to make sensible and evidence-based decisions to keep

themselves safe and as engaged as possible in normal, everyday activities throughout the pandemic.

Authors' contributions Victoria J Forster and Fiona Schulte contributed equally to the manuscript.

Funding Victoria J Forster has no funding to disclose. Fiona Schulte is supported by the Alberta Children's Hospital Research Institute, the Charbonneau Cancer Research Institute, and the Daniel Family Chair in Psychosocial Oncology.

Data availability The data that support the findings of this study as well as the ethical approvals regulating this research are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

Compliance with ethical standards

Competing interests The authors declare that they have no competing interests.

Code availability Not applicable

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