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Cancer survivorship care during COVID-19—perspectives and recommendations from the MASCC survivorship study group

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This editorial draws on the authors' experiences and the results of a survey of cancer professionals to contextualize the major disruptions taking place globally in survivorship care as a result of the COVID-19 pandemic. Cancer survivors' follow-up care has been severely affected due to increased risk of infection associated with hospital attendance, limited workforce availability and other resource constraints, implementation of new protocols to screen patients impacting workflow, and concerns of patients and health care providers about risk of infection [1]. Evidence-based recommendations on how to manage cancer survivors in a pandemic are lacking and much of the general guidance (such as CDC guidelines) [2] suggests that clinic visits for cancer survivors, including routine surveillance visits to detect cancer recurrence, should be postponed [3]. Such a situation is problematic especially if the pandemic is long lasting, leaving important survivorship issues and concerns unaddressed. In the absence of appropriate guidelines, cancer survivors are at

increased risk of inappropriate or inconsistent follow-up care that could have far-reaching and even life-threatening results.

The Multinational Association of Supportive Care in Cancer (MASCC) Survivorship Study Group sought input from members of the Survivorship Study Group to describe their responses to the impacts of COVID-19 on survivorship care, in the hope of identifying how members and their respective institutions have modified cancer survivorship practices and services during COVID-19 in order to identify major challenges of survivorship care delivery and strategies of addressing them. The intent of this exercise has been to scope the breadth and variations in response internationally, highlighting further opportunities to advance survivorship care after the pandemic. In total, 38 members (including physicians, nurses, dentists, clinical researchers, a radiographer, and a pharmacist) from the Asia-Pacific (Australia, India, and Singapore), European (Italy, Portugal, The Netherlands, and the UK), North American (Canada, Mexico, the USA), and South American (Brazil) regions provided their input through a qualitative survey conducted April 22 to 29, 2020.

The results show that post-treatment follow-up care of cancer survivors has dramatically changed as a result of COVID-19. Nearly everyone reported that they have replaced all face-to-face appointments with telehealth (either the telephone or videoconferencing through digital platforms). Some services have redirected cancer survivors to larger facilities (such as government hospitals) as they had insufficient capacity to respond to cancer survivors' needs.

Most respondents indicated that they have had to delay and/or cancel follow-up appointments for patients, unless urgent care was required. Conversely, a handful of respondents stated that they have not needed to change the frequency of their cancer survivor appointments. Some indicated that survivors were limited in their ability to receive timely care from their primary care providers (PCPs) and as such, certain cancer survivorship services have also taken up tasks usually provided by PCPs, such as managing patients' comorbidities.

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Where possible, telehealth has largely replaced face-to-face encounters. However, respondents described numerous barriers to telehealth adoption in the clinical settings. These barriers include limited access to technology, lack of policies for reimbursement and/or funding of telehealth, and safety/privacy concerns. Several respondents expressed concerns regarding the increased risks of anxiety and distress they are perceiving among cancer survivors related to the use of telehealth (e.g., anxiety about believing that they need to have a direct physical encounter to communicate effectively about how they are feeling or any symptoms they may be experiencing). Besides cancer survivors, respondents also indicated that there is a need to increase clinicians' acceptability of and skills in using telehealth to improve adoption.

Respondents provided concrete examples of how they modified survivors' treatment and follow-up plans in the context of the pandemic. Certain non-urgent surveillance (such as mammograms and diagnostic tests) have been delayed at some institutions. Infusion appointments related to the receipt of certain medications, such as those to prevent or treat bone loss, have also been postponed. Conversely, pharmacological therapies including curative adjuvant targeted therapies, ovarian suppression therapies and endocrine therapies appear not to have been disrupted. In collaboration with pharmacies, home delivery services have been used to provide refills on oral anticancer therapies. Respondents also mentioned that survivors were encouraged to practice home rehabilitation; however they did not further describe any details of such approach.

When asked whether they utilized any specific strategies to triage survivors' urgent needs during the pandemic, most respondents expressed that they relied on survivors' self-reported signs and symptoms presented during telehealth consults to determine whether urgent care was required. Some referred patients directly to a "referral clinic" in order to triage survivors' needs. A handful of respondents stated that they did not utilize any specific strategies to identify or prioritize survivors' needs. One reported that their institution implemented an online short questionnaire (PROFILES registry) [4] to determine patient needs, especially among those who were participating in their institutions' ongoing (research) studies. Another reported that their institution implemented the Distress Thermometer (DT) and Problem Check List to identify patients and survivors who were having clinically important distress and needed urgent care.

Most respondents advocated for the wider use of telehealth and online platforms for post-treatment survivorship follow-up after the pandemic is resolved. Other suggestions to improve care after the pandemic included the routine use of virtual exams to observe images (e.g., mammography, CT scan), and the use of effective triaging of survivors' needs over the phone, as well as strategies to improve the acceptability of telehealth among patients (such as the use of telehealth only

after the first face-to-face appointment). No respondents described how physical examination requirements are being addressed via telehealth. Respondents also suggested further developments in cancer services at the home, which might include expanding the role of community pharmacies in providing oral anticancer therapies, as well as cancer nurses in delivering cancer and supportive therapies at the home.

The survey yielded insights into future research opportunities for survivorship care after the pandemic. For example, future research could explore the possibility of lengthening the period of follow-up and reducing the frequencies of reviews. However, some suggested research was needed to investigate if the duration between follow-up care plan contact points was expanded, particularly to determine if there is an adverse impact on the ability to measure and respond to survivors' symptoms.

Suggestions for future practice development were also offered such as the need to consider the benefits and practicality of implementing alternative models of care (such as shared-care, PCP-led care, nurse-led care, and self-management), or engaging dedicated care coordinators to better triage survivors' needs. The use of alternative care models or coordinators may free-up oncologists to focus on acute patients requiring urgent care. Furthermore, minimizing unnecessary presentations to acute care facilities may reduce the risk of survivors contracting infections.

Based on the issues and opportunities highlighted by respondents, we propose three priority areas of survivorship care that require further research and practice development efforts:

1. Triage of immediate needs of cancer survivors: The lack of standardized methods for triaging the immediate needs (physical, psychosocial and spiritual) of cancer survivors for urgent care during COVID-19, as highlighted by respondents, has likely reflected practices that existed prior to COVID-19. Although a range of tools are available (e.g., the DT), such tools are not routinely implemented in survivorship settings. Screening for survivors' needs and the prioritization of care often requires a highly contextualized approach consistent with the local setting and resources [5]. Implementation of a standardized method to screen for, and manage, the immediate needs of cancer patients at each cancer center is likely helpful for future management of crisis and pandemic situations. The use of electronic patient reported outcomes and further developments in ecological momentary assessment technologies will likely advance this agenda [6, 7].
2. Tele-survivorship care: In light of the increased international adoption of telehealth in the cancer and primary care communities, the development of standardized recommendations on broader use of tele-survivorship follow-up (with or without the supplement of other mobile

health technologies) is a priority. Such recommendations should include guidance on identification of patients suitable for tele-survivorship follow-up; training requirements for practitioners, patients and caregivers; solutions for addressing teething issues and barriers at the clinical, organizational and system levels (including funding and reimbursement arrangements) [8]; and ethical and cultural considerations (i.e., accessibility of, and resources required for, telehealth and technological platforms, cultural appropriateness and patient preferences) arising from broader use of telehealth and technology. It is clear in the literature that addressing the above issues will accelerate the adoption of tele-survivorship care [8, 9]. Further implementation research efforts should include planning for and evaluation of reach, effectiveness, adoption and maintenance [10, 11], ensuring telehealth delivery is at least non-inferior to face-to-face delivery as well as cost effective across various settings.

3. Alternative models of care: The limitations of survivors' ability and willingness to attend tertiary care centers during COVID-19 have created an opportunity for cancer care practitioners to de-centralize or delegate care from the specialist setting. Alternative models of post-treatment follow-up care have been proposed but with varying levels of uptake internationally [12, 13]. There is an ongoing debate about "who" should deliver survivorship care, and "which" models of care are most effective in delivering quality of care. We support the view that there is no one-size-fit all model and we call for a focus on "what" constitutes quality [14], within the specific contexts of health services and resources. Again, we call for robust implementation research designs planning for and measuring the various aspects of program implementation including effectiveness of such alternative models. Specifically, practitioners working under different reimbursement models (e.g., private insurance, government) will need to have worked out new payment schemas to be able to maintain their programs. A personalized pathway approach is the next logical step. There is growing interest and ongoing efforts in developing the evidence base and practice for risk stratification and need assessments, mainly in the USA [15–17] and the UK [18]. We call for efforts and attention from the international survivorship community to advance the science and practice across all countries.

In summary, the pandemic has led us all to significant challenges with survivorship care. Survivors are in unprecedented situations of being "more on the outside looking in", even with the advance of telehealth solutions. Programs to address their needs in these challenging times are often being made up in "near real time" to respond and therefore are by their very nature untested (e.g., increases in

home rehabilitation initiatives), and the inconsistencies in the delivery of care may jeopardize the success of this vulnerable group. Effective, evidence-based guidelines are sorely needed. Nevertheless, these challenges have also given us opportunities to identify, develop, test and implement creative solutions and to develop guidelines to facilitate consistency in survivorship care. Moving beyond the pandemic, MASCC should serve as one of the most accessible global platforms for members to partner and develop recommendations, standards and policies to narrow the current gaps in cancer survivorship, with an ultimate goal to improve the quality of survivorship care as a whole.

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Compliance with ethical standards

Conflict of interest The authors declare that they have no conflicts of interest.

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