




Readdressing the Needs of Cancer Survivors During COVID-19: A Path Forward

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Abstract

The growing number of cancer survivors and the high prevalence of cancer-related physical and psychosocial effects pose important and pressing challenges to health systems. The coronavirus disease 2019 (COVID-19) pandemic has led to further stressors on cancer survivors and health care systems. As the pandemic continues to have substantial impact on the world, it is critical to focus attention on the health care needs of cancer survivors. In this commentary, we propose an adoption of essential steps that should be part of a continuous adaptive approach to promote effective cancer survivorship care during on-going COVID-19 waves and beyond.

Over 17 million individuals in North America (1) and millions more around the world (2,3) are living with a personal history of cancer. Before coronavirus disease 2019 (COVID-19), the growing number of cancer survivors along with the high prevalence of cancer-related side effects posed important and pressing challenges to health care systems. The pandemic has led to further stressors on cancer survivors and health care systems (4-6). Earlier in the pandemic, several editorials were written to highlight the potential effects of COVID-19 on the health and health care of cancer survivors (4,6,7). Although suspected yet unconfirmed at the time, recent studies identified cancer diagnosis as a risk factor for acquiring COVID-19 (8) and for its associated negative outcomes, including morbidity and mortality (9-12). Specifically, people at risk are older, have comorbidities, currently receiving chemotherapy, have lung cancer or hematological malignancies, and have completed therapy within 5 years (11-14). After the initial disruptions and delays in routine cancer treatment and follow-up (9,15,16), strategies were implemented to reduce risk of exposure and minimize in-person visits (15,17) along with the development of pandemic-focused priority care guidelines (18,19). While necessary, the potential negative consequences of these changes in health care delivery are

concerning. These concerns were highlighted in a recent editorial by Norman Sharpless, Director of the US National Cancer Institute, in which he noted a substantial decline in screening tests resulting in delayed diagnosis and suboptimal care for people with cancer since the start of the pandemic, which will likely have an impact on cancer mortality (20). Further, a recent article that examined the impact of COVID-19 on cancer care across the globe found 88% of centers faced challenges in providing usual cancer care, and up to 80% of patients in some centers had exposure to potential harm (15). Survivors have also reported negative consequences of COVID-19 on cancer care and follow-up (21,22). Because the duration and course of the pandemic are uncertain, it is crucial that attention be placed on resumption of services along the cancer care continuum when safe and feasible (20,23).

In this commentary, we go beyond the previously published perspectives to propose the adoption of essential steps that should be part of a continuous adaptive approach to find the optimal balance between minimizing the negative impact of the fluctuating COVID-19 pandemic while promoting effective cancer survivorship care (see Figure 1). Our approach is based on a previously published model for cancer diagnostic services (24).

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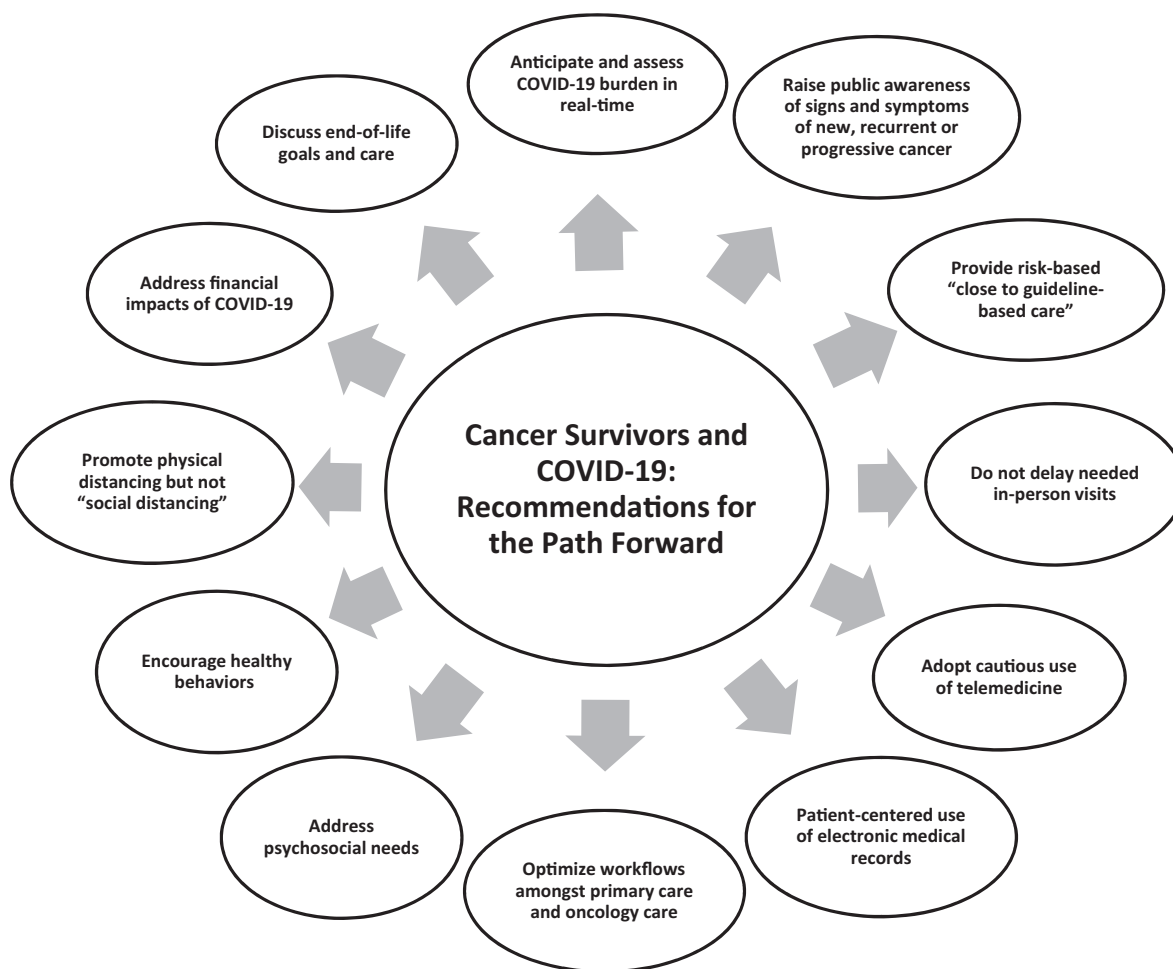


Figure 1. Readdressing the needs of cancer survivors: recommendations for the path forward.

Proposed Path Forward

In guiding this commentary, we sought to capture the rapidly evolving evidence and to include perspectives of multiple stakeholders. First, we reviewed numerous sources, including relevant literature and national and international guidance statements (ie, American Society of Clinical Oncology [ASCO], European Society of Medical Oncology, American Society of Therapeutic Radiation Oncology, and Cancer Australia) and advocacy group recommendations (eg, National Coalition of Cancer Survivorship, and American Cancer Society). Second, we drew insights from 2 Twitter chats focused on COVID-19 and its impact on cancer survivors. The first was hosted by Cancer Survivor Social Media (#CSSMchat) on April 15, 2020; the second was hosted on May 16-17, 2020, by the Radiation Oncology Journal Club (#radonc #jc). Both events included participation by the authors, patients and advocates, and colleagues around the globe, and discussions were based around the themes of potential impact on survivors and the need for action to mitigate the impact.

Anticipate and Assess COVID-19 Burden in Real-Time

With the global pandemic marked by ongoing temporal and spatial variation, the development of appropriate policy and health care delivery planning requires projections of possible

COVID-19 scenarios at the community, regional, and national levels (25). The use of consistent measurements of objective and comparable data is vital to assess the effectiveness of mitigation strategies and inform ongoing efforts (26). Because the prevalence of COVID-19 is critical in driving decisions, collaboration and sharing of accurate data among health care providers and public health agencies are paramount. This, in turn, results in a risk-based triaging of available resources and an assessment of care capacity for cancer survivors.

Raise Public Awareness of Signs and Symptoms of New, Recurrent, or Progressive Cancer

COVID-19 has led to decreased use of health care services, with priority placed on initial cancer diagnosis and treatment (15). Cancer survivors may have also been fearful of coming into health care settings due to concerns about susceptibility, leaving them to manage physical and practical issues and worries on their own (5,27-29). While there has been recent public messaging advising patients to report unusual symptoms, these have not focused on those with prior cancers. Effective outreach involves collaboration on local, regional, and national levels targeted to both patients and caregivers and must be a priority across the cancer care continuum. Although patient education is an important aspect of delivering quality oncologic care, it is

now even more important to educate patients to monitor and report any suspicious symptoms indicative of new, recurrent, or progressive disease. Public health agencies, cancer societies, charitable organizations, and academic centers should develop and disseminate information specifically tailored for those patients with prior cancer.

Provide Risk-Based “Close to Guideline Care”

Posttreatment follow-up care of cancer survivors has dramatically changed as a result of COVID-19, and many surveillance visits and imaging have been delayed or cancelled (5). Although the majority of the guidelines provide specific frequency ranges for surveillance testing (such as every 3-6 months), most are based on consensus rather than evidence. As such, it may be reasonable to delay surveillance during COVID-19 surges based on medical providers' consideration for individual factors, including disease type and treatment exposures as well as COVID-19 risk factors. Symptom-based monitoring, which may be remote, may offer benefits over routine, “traditional” surveillance (30). It is important that in considering surveillance modifications, medical providers take caution in that some patients might perceive this as lack of standard care and thus experience anxiety. Sensitivity toward and adjustment of surveillance modalities to patient preference may be needed. Patient resources regarding the impact of COVID-19 on cancer care have been developed and can be helpful in preparing patients and their families to understand how the pandemic will affect care provision (ie, European Society of Medical Oncology, ASCO Cancer.Net).

Adopt Cautious Use of Telemedicine

Telemedicine with bidirectional messaging to facilitate self-reported monitoring of cancer patients with COVID-19, including any disease-specific or social concerns (31,32), can play a meaningful role for cancer survivors. Although telemedicine is not new, its accelerated dissemination was precipitated by the pandemic (33), and it is poised to become an important pillar of cancer care (34). However, although secure telemedicine with its incorporation of risk-benefit balance has been a useful and important tool to deliver care since the onset of the pandemic, it is not in itself the solution (35). Efficient and meaningful telemedicine requires training for patients, caregivers, and clinicians as well as having the “right” technology, appropriate infrastructure, and private space for the virtual visits. Impaired hearing and vision, linguistic barriers, cultural limitations, and cognitive deficits in patients pose further challenges necessitating a more personalized virtual approach. Often there are digital inequalities or disparities in both the ability to access and to use telemedicine within local, regional, national, and global populations (36,37). In such cases, alternative routes of communication such as telephone conversation can be potentially helpful. Communication guides that may assist clinicians with oncology-specific language to respond to patient questions about changes in delivery of cancer care during the pandemic are available online (38,39).

There continue to be widespread issues with regulations regarding financial incentives and reimbursement associated with telemedicine. To address this evolving situation, ASCO recently issued an interim position statement on telemedicine in cancer care that included recommendations on federal and state coverage, health equity, patient education, and research

(40). With the current crisis posing additional challenges to communities that have traditionally faced barriers to health care access, sole reliance on telemedicine is not advised, and appropriate triaging considering the risk of COVID-19, the urgency of the patient needs, and patient preferences should dictate the route of communication (4). Moving forward, it is important that health care organizations expand beyond the traditional center walls to leverage multidisciplinary community-based care to serve those for whom virtual care is inappropriate or inaccessible (41).

Do Not Delay Needed In-Person Visits

Although remote monitoring using telemedicine may be adopted, when required, physical examination should not be avoided (42). There has been a rapid reorganization of cancer systems to ensure timely and essential cancer care while minimizing risk of exposure to COVID-19 (23). Recent guidance from organizations such as ASCO provides immediate and short-term recommendations that cancer centers and oncology practices can adopt (19). It is important to emphasize that there is no “one size fits all” approach to delivering cancer care during the COVID-19 surges, and individualized treatment decisions must be made. Priority should be given to those whose treatments and testing have been delayed during “shutdown” and driven by benefit vs risk analysis as well as therapeutic intent (43-45). In cases where face-to-face clinical encounters are warranted, safety should be optimized through patient outreach and education. Patients should be given practical advice and instructions to encourage safe behavior when coming in for routine checks or other follow-up care. Health care facilities can promote adaptation to the “new normal” by delivering “care with caution” following standard COVID-19 precautions.

Patient-Centered Use of Electronic Medical Records

Recognizing the challenges of telemedicine, an opportunity to empower patients is provided by availability of real-time online access to electronic records, including encounter notes written by clinicians (referred to as “open notes”) through patient portals (46). Such practice exists in Nordic countries as well as several institutions in the United States and continues to grow worldwide (47-49). Encouragingly, new federal laws in the United States mandate that providers must extend open notes to all patients starting from November 2, 2020 (50). Although there is concern that patients' access to their oncology notes will trigger anxiety or confusion, research to date suggests that patients find this access to be useful; report improved understanding about their diagnosis, treatment risks, and side effects; and learn important information that they had missed during clinical visits (51-54). Accessibility to open notes has been cited as crucial for patients' mental well-being (46). For patients with reliable internet access, patient portals can also allow remote communication, education, and scheduling of follow-up appointments and could support the electronic collection of patient-reported outcomes. The value of open notes can be optimized by improving both oncology professionals' clarity in online documentation and maximizing their use of tooltips as well as patients' understanding of the benefits and risks of accessing their medical records (50). The use of open notes is highlighted by the pandemic and has the potential to serve patients in the future.

Optimize Workflows Among Primary Care and Oncology Care

Adoption of evidence-based, innovative models of care, including shared follow-up and survivorship care along with streamlined collaborative workflows among primary care and oncology services, was insufficient in the pre-COVID era. The need for such a workflow has been intensified by the pandemic and can facilitate timely evaluation of potential cancer symptoms as well as divert COVID-19 evaluations for cancer patients to nononcologic settings, thus decreasing risk of transmissions among this vulnerable cohort. The fundamental role of primary care may also be well-poised to identify cancer survivors at risk of suboptimal or delayed surveillance due to noncompliance. Further, optimization of primary care with efficient use of triage-based telemedicine or personal interaction may support cancer patient follow-up and assist in sustaining their physical (ie, management of chronic medical conditions) and mental health. To support this, it is important to establish and embed processes and infrastructure that encourage the development and sharing of patient follow-up care plans between multidisciplinary health professionals who are providing survivorship care. Resources and education of multidisciplinary health care providers to support delivery of person-centered and evidence-based models of follow-up and survivorship care are needed (42). Development and use of standardized templates to support care coordination and agreement of alternative follow-up shared care arrangements have been proposed (42). Further, processes to support rapid communication between primary and tertiary care settings for clinical issues requiring cancer specialist consultation or advice need to be established (42).

Address Psychosocial Needs

The United Nations has warned of a global mental health crisis due to COVID-19 (55). Cancer survivors already face uncertainty and are at higher risk of depression and anxiety compared with the general population (56-58). COVID-19 has likely exacerbated this due to lack of access to screening and recommended care coupled with worry over increased susceptibility to contracting COVID-19 (7,59). Physical distancing protocols, which continue in most areas of the world, have the potential to amplify anxiety, distress, and depression. Additionally, socioeconomic and sociopolitical disparities can further exacerbate psychological morbidity in cancer patients (60-62).

Proactive steps can be taken to address the psychosocial needs of cancer survivors (63). To begin, it is important to validate the anxiety that individuals are feeling; compassion and value-based approaches may be beneficial (64). The next steps involve identifying those who need extra support can be facilitated through simple screening tools (ie, distress thermometer) as well as emerging tools to assess fear related to COVID-19 (65). Moving forward, it is critical that expansion of mental health services is prioritized to increase the capacity to address the challenges caused by the pandemic. The use of triaging and stepped care approaches (66) will require systems that are well designed to screen, identify, and deliver this care. Initiatives such as Helplines (ie, Cancer Support Community Helpline) and peer “check-in” could make a difference in the early stages of social isolation (67). Further, the use of telemedicine and other technology platforms can be vital components of stepped care for acute mental health crisis management as well as nonurgent care and support (63).

Encourage Healthy Behaviors

For many, COVID-19 and the need to self-isolate or quarantine has had a very negative impact on lifestyle behaviors, including physical activity, diet, sleep, and alcohol consumption (68-74). Given the importance of promoting physical and mental health and overall well-being (75), scientific and medical organizations including the World Health Organization have released recommendations to promote physical activity at home during the COVID-19 pandemic. The recovery and quality of life of cancer survivors can be at risk with surges of COVID-19, and cancer survivors may be particularly vulnerable to the impact of the pandemic on lifestyle behaviors. Physical inactivity, sedentary behavior, and poor nutrition are already highly prevalent in cancer survivors both during and after treatment (76) and are associated with chronic medical conditions as well as overall poor physical and mental health and increased mortality risk (77-80). With limited access to gyms and exercise programs along with the need to enact more strict physical distancing measures, participation in healthy behaviors among cancer survivors is likely to further decline. At the same time, social distancing may present an opening to make lifestyle changes because some typical barriers that interfere with an active lifestyle adoption (eg, lack of time, work, traffic) have been removed (81). Clinicians and other health care practitioners should proactively prescribe physical activity to their patients during the pandemic and encourage other healthy strategies such as sleep hygiene and nutrition (7). Verbal coaching, brochures and pamphlets, and effective use of social media platforms can assist with promoting healthy behaviors. Remotely supported home-based exercise programs that integrate safe and simple exercises may be recommended (82). Cancer survivors who are exercise-naïve or who have preexisting health problems and/or exercise contraindications should consult with their primary care provider, oncologist, and/or an exercise professional before starting any new exercise program; initial supervision is recommended for these individuals (83). As with any lifestyle change, cancer survivors should be encouraged to develop small realistic goals that can be progressed over time (84).

Promote Physical Distancing, Not “Social Distancing”

Cancer survivors should be counseled that social interactions are not just acceptable but also beneficial (as long as local health strategies and measures taken to ensure safety are not violated). As with the exercise activities described above, the use of virtual social platforms may be helpful in increasing social interactions in a safe manner (85). Many gyms, places of worship, and social groups such as book clubs have transitioned to online platforms. Workplaces are conducting meetings and creating virtual workspaces for people to connect over video connections. Cancer centers and community cancer support programs have also developed online programs that should be encouraged to help support cancer survivors. Future efforts should be geared towards developing more engaging and intuitive platforms to encourage meaningful social interactions during pandemic waves and beyond.

Address Financial Impacts of COVID-19

Cancer survivors already face hardship associated with financial burdens and are particularly at risk for additional negative

financial effects as a result of COVID-19, thus affecting quality of life as well as morbidity and mortality (86–89). Survivors whose employment is deemed “essential” and cannot be conducted from home may have to weigh the benefits of work with potential increased exposure depending on their occupational risks and may be forced into temporary unemployment. For others, their financial situation gives them no option but to continue going to work, potentially resulting in increased risk of COVID-19 transmission and associated distress (41,90). This must be considered in light of the research that shows that gaining new employment after job loss is more difficult for cancer survivors compared with the general healthy population (91). Those individuals who are self-employed or work for small employers may also face unique short- and long-term uncertainties. Being able to work has been shown to affect the quality of life of cancer survivors because having a job contributes to feelings of normalcy, resilience, and meaning (92). Being unemployed can also result in loss of health insurance benefits, particularly for those in the United States. Such a financial situation can be detrimental for survivors who depend on insurance benefits for care and can result in psychological stress. Moving forward, it will be essential to assess and discuss access to care and risk of financial toxicity and to facilitate access to social work and resources about loss of health coverage (ie, National Coalition of Cancer Survivorship).

Discuss End-of-Life Goals and Care

Although engaging patients in goals of care discussions has long been emphasized, the pandemic has highlighted the importance of goal-concordant care in several ways. The additional risk of COVID-19 has underscored the importance of proactive advance care planning for all oncology patients (93). As previously noted, cancer survivors most likely to develop severe COVID-19 will be older and have greater burden of chronic illness. These may (or not) be the same individuals who may wish to forgo prolonged life support and/or who may find their quality of life unacceptable after prolonged life support (94). In the context of the pandemic, advance care planning prior to and at the onset of serious acute illness should be a key objective. Clinicians should include clear documentation of these discussions, especially if they take place during a telemedicine visit. Several online resources can guide providers to carry out these conversations (39,95–98).

As the COVID-19 pandemic continues to evolve and emerge in new areas or reemerge or abate in others, active cancer treatment as well as other urgent and emergent conditions will likely take priority. The pandemic has uncovered and exacerbated many challenges and highlighted the limitations of traditional health care delivery systems. While focusing on the needs of all survivors, it is vital to address and readdress the needs of long-term cancer survivors who are already vulnerable to the physical, psychological, and financial effects of cancer that are now amplified by the COVID-19 pandemic. Health care professionals, policymakers, and patient groups must take a systematic approach to evaluate, adopt, and refine measures needed to improve the health of cancer survivors during and beyond this pandemic.

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