



# Impact of the coronavirus disease 2019 pandemic on delivery of and models for supportive and palliative care for oncology patients

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## Purpose of review

Supportive and palliative care services have been an important component of the overall COVID-19 pandemic response. However, significant changes in the provision and models of care were needed in order to optimize the care delivered to vulnerable cancer patients. This review discusses the evolution of palliative and supportive care service in response to the pandemic, and highlights remaining challenges.

## Recent findings

Direct competition for resources, as well as widespread implementation of safety measures resulted in major shifts in the mode of assessment and communication with cancer patients by supportive care teams. Telemedicine/virtual consultation and follow-up visits became an integral strategy, with high uptake and satisfaction amongst patients, families and providers. However, inequities in access to the required technologies were sometimes exposed. Hospice/palliative care unit (PCU) bed occupancy declined markedly because of restrictive visitation policies. Collection of patient-reported outcome (PRO) data was suspended in many cancer centers, with resulting under-recognition of anxiety and depression in ambulatory patients. As in many other areas, disparities in delivery of supportive and palliative care were magnified by the pandemic.

## Summary

Virtual care platforms have been widely adopted and will continue to be used to include a wider circle of family/friends and care providers in the provision of palliative and supportive care. To facilitate equitable delivery of supportive care within a pandemic, further research and resources are needed to train and support generalists and palliative care providers. Strategies to successfully collect PROs from all patients in a virtual manner must be developed and implemented.

## Keywords

coronavirus disease 2019, disparities, hospice, models of care, palliative and supportive care, patient-reported outcomes

## INTRODUCTION

Provision of supportive and palliative care is now widely recognized as a critical component of high-quality treatment of patients with life-threatening illness, such as advanced cancer, improving not only the patient experience but also objective clinical outcomes. As different healthcare systems and jurisdictions have recognized the benefits of distinct, dedicated palliative and supportive care services, various models for care delivery have arisen at the systems and local levels. From hospice/palliative care unit (PCU)-based end-of-life care for individuals in the terminal phase of illness, through inpatient care in a larger mixed setting (within general hospitals, nursing homes, long-term care facilities), to community-based palliative care services provided

in the ambulatory and home-care settings, interdisciplinary palliative and supportive care teams have integrated into cancer care systems. Inpatient palliative care is itself delivered through a variety of

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## KEY POINTS

- Supportive and palliative care delivery has been impacted by the COVID-19 pandemic, with a significant increase and reliance on telemedicine and video conferencing technologies; barriers to meaningful communication must be consciously minimized in order to facilitate successful conversations.
- Stringent visitation policies during the COVID-19 pandemic reduced hospice/PCU admissions, while inpatient palliative care consultations increased.
- For palliative care inpatient consultations that were not in-person, virtual telehealth consultations provided a satisfactory alternative that had the potential to augment inclusion of family members and multiple interdisciplinary care providers.
- Increased resources and innovative strategies are needed to improve compliance with virtual Patient Reported Outcome completion at cancer centers in order to maintain quality of patient care.
- The COVID-19 pandemic exacerbated disparities in delivery of supportive and palliative care to disadvantaged groups; new strategies and resources are needed to ensure equity of access, delivery and location of supportive and palliative care services.

models, including dedicated PCUs within larger general hospitals, palliative care consultation services, and coordinated models wherein palliative care is integrated within emergency departments or ICUs. Long-term care-based or nursing home-based palliative care consultation services were established to address the unique needs of these patients, who typically have multiple advanced illnesses and significant symptom burden, functional dependence and cognitive impairment; this approach has resulted in quantifiably improved symptom burden and decreased hospitalizations [1,2]. Home-based palliative care programs have been shown to decrease acute care hospital utilization and increase utilization of hospice/PCU care, lower healthcare costs, and allow patients to die in their homes [3,4]. Ideally, an overarching system should coordinate delivery of palliative and supportive care across all of these settings, for the individual patient.

Research has shown that palliative and supportive care can substantially alleviate health-related suffering, and improve quality of life, communication, and satisfaction with care, as well as survival outcomes [5–11]. On the basis of these data, several national organizations, including the American Society of Clinical Oncology (ASCO), have endorsed the early involvement of palliative care providers for patients with advanced cancer, alongside usual

oncology care. On the basis of these endorsements and the primary evidence upon which they are based, specialized provision of palliative care has become firmly embedded in oncology programs [12–14].

The novel coronavirus, SARS-CoV-2, emerged in late 2019, and dramatically altered conventional healthcare delivery worldwide. Early reports implicating visits to a cancer center in transmission of the COVID-19 virus to vulnerable cancer patients [15,16<sup>a</sup>] triggered severe measures to curtail in-person clinic visits. There was a marked transition to digital health strategies and remote/virtual services to limit exposure [17]. There was an overall increase in demand for healthcare services, requiring redeployments and strategies to involve healthcare workers outside of their usual practice, impacting many areas of subspecialty healthcare delivery. Research efforts in cancer centers were curtailed to promote social distancing and minimize in-person activities for both patients and staff. Research priorities shifted rapidly to understanding the epidemiology of COVID-19, SARS-CoV-2 virus transmission and prevention strategies, vaccines, treatments, socioeconomic impact, and health system policies for the prevention and control of the disease. Collection and analysis of patient-reported outcomes (PROs), previously an evidence-based priority in cancer centers worldwide [18–20], was deprioritized, and became inconsistently applied.

As the pandemic continues to evolve globally, palliative and supportive care has been highlighted as an essential part of the pandemic response [21,22]. In this context, healthcare administrators and practitioners alike recognize the key roles of palliative care teams in identifying and addressing goals of care, supporting effective symptom management, providing psychosocial support and bereavement care for family members, as well as supporting other healthcare workers who are overwhelmed, stressed, and traumatized by their experiences with COVID-19 illness [23,24<sup>a</sup>,25,26]. Modification of previously existing models of care in order to support patients and care teams during this unprecedented time has been and is critical in the short-term; long-term implications must also be addressed and should influence future policy decisions locally and globally. This review discusses the impact of the COVID-19 pandemic on the provision and delivery of supportive and palliative care in cancer patients, with a view to enhancing our preparedness as a global community.

We conducted a literature search of Medline, PubMed, EMBASE, CINAHL, and Cochrane Library (1 January 2020 to 21 April 2022) for studies, including reviews, editorials and original research, on

models of palliative and supportive care in relation to the COVID-19 pandemic, and themes for discussion were identified. The references of identified relevant reviews were also screened. Articles were excluded if they did not report on palliative care models, COVID-19, did not include English translations or were not relevant for palliative care patients in a cancer setting. The authors' geographical location is Toronto, Canada.

## WIDESPREAD ADOPTION OF TELEMEDICINE

While some providers offered telephone-based or video-based real-time assessments to patients in remote areas prior to the pandemic, utilization of these platforms, as well as secure video conferencing for multidisciplinary case discussions, escalated exponentially within the early months of the pandemic [27–32]. Whereas patients who were to be seen in person were mandated to come alone for their visit at the cancer center, virtual platforms allowed for multiple family members/caregivers to participate in discussions with healthcare providers. Given the initial uncertainty about modes of SARS-CoV-2 transmission, many patients and families were more accepting of phone/video visits than of in-person consultations. This also helped patients overcome obstacles related to disability and mobility issues as they did not have to attend in-person clinics. Some supportive care services, such as occupational therapists and speech language pathologists, initially found the transition to virtual care challenging, although the majority were able to adapt and continue to provide high-quality and well tolerated care [33,34]. Government and regulatory agencies made significant adjustments to allow broader acceptance and financial reimbursement of telehealth [35,36].

Several groups have shared their experiences with establishing a telemedicine-based palliative care program [28,37–39,40,41,42]. Chavarri-Guerra *et al.* [40] describe the feasibility of providing supportive and palliative care using telemedicine to patients with advanced cancer in Mexico, despite low availability of resources and patients with significant symptom burden. The supportive care clinic team at MD Anderson describe their rapid transition to virtual care using FaceTime and Zoom, allowing them to maintain volume of clinical encounters despite an 86% reduction in in-person visits; this approach enabled continuity of care in support of patients who were evaluated virtually at a tertiary care cancer center [41]. Ritchey *et al.* [28] created a business case for provision of virtual personalized palliative care using iPads, and describe its

implementation at a Veterans Affairs Medical Center. Ankuda *et al.* [38] describe the conception and successful implementation of a novel telephone-based palliative care support line, the 24-7 Palliative Care Help line (PATCH-24). This was developed to service six hospitals within the Mount Sinai Health System throughout New York City during a COVID-19 surge in March of 2020. The structure of the call line, initially developed as a teleconsultation service, but rapidly transitioned to a telemedicine service, allowed a palliative care team to rapidly extend specialist acute palliative care across the health system and was helpful in prioritizing allocation of inpatient palliative care resources.

Early concerns about the potential difficulty of establishing trust and rapport with patients using virtual platforms were, in general, not borne out [43]. Nevertheless, caution and attention needed to be applied to avoid barriers to meaningful communication and successful conversations, particularly around complex topics like mortality and grief. Common themes identified in recent editorials highlight communication strategies that are highly important in virtual visits, such as being present rather than distracted, allowing space for and responding to questions, and validating emotions. A variety of communication tools (e.g. CALMER [44] framework or NURSE [45] statements) can assist in ensuring effective virtual communication. In a guidance document published at the height of the pandemic, Flint and Kotwal [37] summarize key elements of effective virtual communication and strategies to address barriers to successful conversations, providing a framework for telemedicine visits. These include preparation and accommodation, building rapport and trust, having conversation, and responding to emotion.

Palliative care practitioners are also using telemedicine in the inpatient setting, regardless of COVID-19 infection status, as family/caregiver visits have been limited by institutional regulations. Moreover, this can also allow for multiple healthcare professionals to engage with patients/families/caregivers at the same meeting, which can be challenging to coordinate in-person. Limitations on palliative care provider availability can also be addressed in this manner [46]. However, there are potential disadvantages to bear in mind. Virtual conferencing can promote 'work creep', extending work hours for palliative care providers already stretched to their emotional limits. Also, use of telemedicine platforms can accentuate disparities between individuals and families that are 'technology savvy' compared with those that can only manage telephone visits. Some patients/families may not have access to technology that enables telehealth,

and be limited by poor internet connectivity, or technical challenges in navigating telehealth systems [40<sup>□</sup>]. As a society, we now recognize that these barriers are particularly encountered by vulnerable populations that most need medical attention during the COVID-19 pandemic, intensifying healthcare inequities [47<sup>□</sup>,48].

## IMPACT OF COVID-RELATED RESOURCE LIMITATIONS

Some palliative and supportive care resources became limited because of direct competition with requirements for active treatment of patients infected with COVID-19. Other resources were intentionally limited to protect patients, families, and staff from acquiring COVID-19. Hospice/PCU admissions decreased uniformly worldwide because of changes in admission criteria and visitation policies. Although some hospices and PCUs accepted COVID-19-positive patients, most opted not to [49,50]. In addition, hospice and PCU policies that banned visitors made hospice admission unacceptable for many families, as this would result in their loved one dying alone [51<sup>□</sup>]. In the city of Palermo, hospice unit bed occupancy dropped from 95 to 40% [49].

Delivery of palliative and supportive care to hospital inpatients escalated during the pandemic; in the case of cancer patients, this trend may, at least in part, have reflected decreased utilization of hospice/PCU care [52]. Notably, an increase in admissions to a general hospital in-patient unit for the express purpose of symptom palliation was observed, as well as an increase in palliative care consult requests for inpatients on general medical wards [53,54]. In the latter context, 39% of patients were assessed in-person, and 61% by virtual means [51<sup>□</sup>], though this ratio varied by institution and jurisdiction. The option of virtual care was embraced by family members/loved ones, physicians, advanced practice nurses, and other team members. Some providers were able to work from home, limiting exposure to COVID, which reduced their own distress and anxiety [55]. As personal protective equipment (PPE) was not required in a virtual setting, more meaningful engagement between physician and patients was ironically often apparent. Family members who were stuck abroad were able to be more involved in decision-making and care of the patient. In one study, 97% of palliative care patients and caregivers who responded to a survey reported that they were comfortable having virtual consultations and visits [51<sup>□</sup>,55]. In this respect, limitations imposed in response to the pandemic did not appear to have adversely affected

delivery of palliative/supportive care. Visitor restriction policies did, however, significantly impact patients, caregivers, and palliative and supportive care service providers. Survey data describe distress in 82% of palliative care professionals when discussing visitor restriction policies with patients and families and difficulty in providing caregivers with support because of enforcement of these policies [56].

As noted, referrals made to the palliative care service from the inpatient wards in general hospitals increased during the pandemic (up to 42%, in one report from Spain); at the same time, there was a corresponding decrease in referrals from the outpatient/primary care setting [53]. Overall, these authors reported no change in the total number of cancer patients treated by palliative and supportive care services during the pandemic, compared with the prepandemic period. Within free-standing designated cancer centers, the burden of COVID-19-related illness was generally low, despite initial fears based on early experience in China. At the MD Anderson Cancer Center, only 4.8% of patients referred to inpatient palliative care were COVID-19 positive [57]. In Northern Italy, health service reorganization resulted in increased volume of cancer patients being managed at the Istituto Nazionale di Tumori, whereas COVID-positive patients were cared for at other facilities [7]. Such adaptive restructuring of models of care are instructive, and should minimize the disruption of palliative care provision to those in need.

From the start of the pandemic, there was a sharp, marked, and sustained increase in admissions to critical care units/ICUs. In many jurisdictions, this was accompanied by an increase in referrals to supportive and palliative care services. However, not all patients who were dying of COVID-19-related disease were referred – for instance, at Mount Sinai Health System in New York City between March and April 2020, out of a total of 151 patients with COVID-19 requiring ICU admission, only 40% received an inpatient palliative care consult. Most strikingly, of the 85 patients who died, 57% received palliative care services. Interestingly, patients who did not receive palliative care services were more likely to be younger and required noninvasive ventilatory support [58<sup>□</sup>]. A potential explanation could be the lack of referrals to palliative care in these younger patients who were not expected to die. Another possibility may have been an attempt not to overburden the palliative care teams, who were thought to be needed by vulnerable cancer patients. In fact, the intersection of these groups appears to have been more limited than initially anticipated. On the basis of data drawn from the multinational



ISARC database of patients admitted to ICU for COVID-19 illness, only 3.6% had a neoplasm (Laura Merson, Oxford University, personal communication). According to a retrospective study of cancer patients dying of COVID-19 at a tertiary referral cancer centre in the UK, 82% were referred to palliative care prior to death [59]. During any future pandemic, training and support in recognizing deteriorating patients should be prioritized, to facilitate provision of palliative care services wherever appropriate.

The impact of the pandemic on models of palliative and supportive care delivery definitely varied by jurisdiction. In Toronto, Ontario, hospice/PCU and inpatient palliative care units experienced low bed occupancy, and high availability, probably because of zero visitor policies, as well as fear of acquiring COVID-19 from other patients [60<sup>11</sup>]. Most inpatient palliative care teams reported that their clinical loads decreased and were below baseline; several teams were redeployed to provide palliative care assistance in long-term care facilities. Teams that indicated above average clinical loads during the first wave of the pandemic provided either community home visits or ambulatory care, rendering support to patients who were avoiding the inpatient acute care system. In contrast, some jurisdictions in India reported diversion of palliative care staff to provide care for patients with COVID-19 infection during case surges, resulting in limited palliative care provided to cancer patients [61]. In terms of other resources, Ontario did not experience a shortage of PPE, and redistribution of patients requiring ICU or inpatient care across the province minimized the need to triage. There were shortages of some medications commonly used by palliative care teams (midazolam, haloperidol, dexamethasone, hydromorphone, and ondansetron) during the first COVID-19 wave, because of increased administration of these in critical care settings [60<sup>11</sup>].

### **COLLECTION OF PATIENT-REPORTED OUTCOME MEASURES**

Prospective studies have shown that patient's quality of life and satisfaction with care are objectively improved by routine PRO capture in cancer centers [62,63]. In addition, routine collection and integration of PROs into clinical care has been widely associated with longer overall survival in cancer patients, better palliative care experiences, as well as more effective identification and referral of patients with occult depression and anxiety [11,18,64]. These benefits are attributable to inconsistent identification of severe symptoms by

clinicians through conventional patient encounters and earlier detection of significant symptoms through PRO completion [11]. PROs also represent a powerful tool to promote healthcare equity by empowering patients to express themselves in a quantifiable and validated manner, reducing the chance that implicit bias could skew the provider assessment and/or understanding of a patient's symptomatology. Unfortunately, the advent of the COVID-19 pandemic rapidly curtailed collection of PROs: in-person visits were minimized, infection control procedures limited handling not only of clipboards/pens but also of tablets/desktop computers, and virtual collection of PROs was typically not prioritized.

At Toronto's Princess Margaret Cancer Centre, routine collection of PROs had become well entrenched prior to March 2020. Ambulatory patients completed the ESAS, a validated self-reporting tool of symptom severity for nine common symptoms of advanced cancer including pain, tiredness, nausea, drowsiness, appetite, wellbeing, shortness of breath, depression, anxiety [65–67] at each clinic visit. In the immediate pre-COVID era, patients used touch pads provided by the clinic to enter their scores and those who had any difficulty navigating the platform, for any reason, were assisted in person by clinic volunteers; this approach yielded a compliance rate in excess of 85%. The direct electronic patient entry prompted real-time review by clinicians, with early intervention as appropriate. At the time of the first wave of the COVID pandemic, touchpads were removed from clinic and patients were seen virtually whenever possible. ESAS completion ceased. Recognizing the risk of under-appreciation of cancer symptom burden, which would be exacerbated by COVID-related anxiety and isolation, we decided to attempt virtual collection of PROs, and prospectively study completion rates.

In a prospective cohort study [68<sup>12</sup>], we found that compliance with ESAS completion was markedly reduced when patients were asked to complete it virtually on an online platform. By contrast, completion of hard copy forms during in-person clinic visits approached 100%, and revealed concerning rates of anxiety and depression. We, therefore, implemented a virtual-mentored approach, whereby an electronic ESAS form was emailed to the patient, and a care team member provided remote support to facilitate completion. This resulted in improved completion rates, and allowed the healthcare team to address severe symptoms that were not captured at the time of the clinic visit. Provision of virtual mentorship entailed considerable investment of resources outside of regular clinic

hours and was not sustainable without additional resources. We anticipate that widespread adoption of this strategy would be hampered by resource limitations.

### **INEQUITIES IN PALLIATIVE AND SUPPORTIVE CARE DELIVERY**

The pandemic has highlighted previously existing disparities in healthcare [69–71], with SARS-CoV-2 infection and adverse outcomes observed disproportionately in ethnic minority groups. Prior to the pandemic, inequities in the provision and delivery of palliative care had been identified, including suboptimal access to services, timing and place of care in economically and socially disadvantaged groups [72–78]. During the pandemic, the rapid expansion and adoption of palliative telemedicine has had the advantages of reducing risk of exposure in vulnerable patients, preserving and extending resources and protecting the healthcare team. However, racial/ethnic-based, language-based, and income level-based disparities were uncovered with respect to telemedicine use [47<sup>22</sup>,48,79].

This ‘digital divide’ not only impacts the immediate care of our patients but also will have long-term consequences on the health of patients from disadvantaged groups. An example of this pandemic-induced exacerbation of inequity has been described by Sisodia *et al.* [80<sup>22</sup>], who compared PRO completion at the Massachusetts General/Brigham hospitals after March 2020, to that observed pre-pandemic. As at our own institution, tablets were removed from clinic and the sole platform for collection of PROs became the patient online portal. Although pre-pandemic in-person use of tablets in clinic was associated with PRO completion rates that were equivalent irrespective of self-identified race or ethnicity, a marked imbalance followed the shift to the patient portal. Patients who self-identified as black completed PROs at half the rate of white patients, and patients who identified as Hispanic had completion rates of less than 5%. These inequities persisted despite several attempted interventions, resulting in PRO data that do not reflect black or Hispanic experiences and that do not facilitate incorporation of their preferences into personalized care, preventing the same level of consideration and individualized medicine that white patients receive, with potentially far-reaching consequences.

Moreover, data from a UK survey showed that over the course of the pandemic, palliative care services were more likely to be provided to ethnic minority patients and their families within an inpatient hospital setting, whereas only 23% of hospice/PCU and 30% of home palliative care teams had

cared for any patients from ethnic minority groups who were dying with COVID-19 [81]. This pattern was seen despite the fact that ethnic minority groups were disproportionately affected by COVID-19, and that community and home care palliative care teams reported that they were busier during the COVID-19 pandemic.

It is incumbent upon us as a would-be just society to recognize and address the inequities in receipt of supportive and palliative care that were made more starkly apparent by the pandemic. Models of care delivery must be assessed for their ability to promote equity, rather than deepen existing inequities. It is necessary that both palliative care providers and healthcare administrators recognize the unintended consequences of well intentioned changes to models of care; this understanding should guide resource allocation, planning, and inform future interventions aimed at improving access for all.

### **CONCLUSION**

The literature supports the use of telemedicine as a strategy to safely provide palliative/supportive care to cancer patients during the COVID-19 pandemic. However, as telemedicine was adopted predominantly for safety reasons, further research is needed to better understand how remote assessments affect patient outcomes in the longer term, as well as healthcare providers’ physical and mental workload and wellbeing. Moreover, standardized telehealth education and training for learners and providers need to be provided. Resource reallocation is essential to ensure that the demand for palliative care services is met. The potential amplification of pre-existing inequities within the healthcare system that can and did arise during the pandemic needs to be recognized, so that individual access to appropriate services, particularly palliative and supportive care [82<sup>22</sup>], can be ensured through better implementation of alternative models for care delivery. Long-term priorities should ensure that equitable provision of palliative care be integrated in pandemic planning.

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## Conflicts of interest

There are no conflicts of interest.

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- of special interest
- of outstanding interest

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