



# Palliative care delivery changes during COVID-19 and enduring implications in oncology nursing: a rapid review

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## Purpose of review

A rapid review was conducted to synthesize evidence of palliative care delivery changes during the COVID-19 pandemic. Changes were synthesized according to the eight domains of high-quality palliative care and enduring implications for oncology nurses beyond the pandemic discussed.

## Recent findings

The most significant changes occurred in the structure and processes of palliative care (Domain 1), where increased utilization of telehealth was critical in circumventing barriers imposed by COVID-19 mitigation. The suboptimal availability of community-based psychosocial supports for patients and caregivers and inadequate health system-based psychosocial supports for healthcare providers were highlighted (Domains 3–5). The pandemic also ushered in an increased emphasis on the need for advance care planning (ACP), where integrating its delivery earlier in the outpatient setting and shifting policy to promote subsequent virtual documentation (Domain 8) were essential to ensure care preferences were clarified and accessible before health crises occurred.

## Summary

Continuing to embrace and sustain systems-level changes with respect to telehealth, psychosocial supports, and ACP are critical to bridging gaps in palliative care delivery underscored by the pandemic. Oncology nurses are well positioned to fill these gaps in care beyond the pandemic by providing evidence-based, palliative care throughout the cancer continuum.

## Keywords

cancer nursing, palliative care, palliative nursing, telehealth, telemedicine

## INTRODUCTION

Rapidly changing public health constraints during the COVID-19 pandemic imposed significant demands on palliative care delivery throughout the cancer continuum [1–3]. Palliative care is an interdisciplinary, holistic approach to alleviating serious health-related suffering for patients and their caregivers (i.e., family members and friends) in the context of a life-limiting illness [4]. Primary (generalist) palliative care for patients with cancer is delivered by oncology teams, including oncology nurses, to address the physical, psychological, and spiritual consequences of care [4,5]. Expert interdisciplinary teams deliver specialty palliative care to handle more complex needs, including refractory symptom management and goals-of-care clarification, and conflict resolution [4,5]. The pandemic has highlighted the critical need for oncology nurses to fully assume their responsibilities to deliver primary palliative care for all patients with cancer,

which includes identifying the need for specialist palliative care input [6].

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## KEY POINTS

- Telehealth utilization is rapidly expanding across healthcare systems, and oncology nurses are well positioned to more comprehensively address the needs of patients with cancer and their caregivers through routine access to telehealth-facilitated palliative care across the cancer continuum.
- Oncology nurse-led interventions are needed to bridge care gaps, facilitate safe care transitions, and connect patients/caregivers to community-based psychosocial support services as cancer treatment increasingly transitions outpatient.
- Psychosocial supports for healthcare providers must be strengthened and integrated throughout healthcare systems to sustain the workforce, mitigate the psychological sequelae of clinical distress, invest in staff resilience, and bolster retention.
- Oncology nurses must reclaim and leverage their role in ACP to proactively clarify goals-of-care and end-of-life preferences across the cancer continuum, which must be supported by flexible implementation and user-friendly documentation policies.

Through a rapid literature review, we aimed to synthesize evidence of palliative care delivery changes brought on by COVID-19, which have enduring significance for oncology nursing beyond the pandemic. The search strategy utilized terminology consistent with three concepts – cancer, palliative care, COVID-19 – and was limited to peer-reviewed articles published within the last 18 months. We synthesized palliative care delivery changes according to the eight domains of high-quality palliative care (Fig. 1) and discussed implications for the future of palliative care supported by oncology nurses.

## FINDINGS

### Domain 1: structure and processes of care

Articles frequently described systems-level transformations in the structures and processes of primary [7<sup>¶</sup>] and specialty [8<sup>¶</sup>,9<sup>¶</sup>,10<sup>¶¶</sup>,11<sup>¶¶</sup>] palliative care during the pandemic. Oncology teams pivoted to conduct early primary palliative care-facilitated goals-of-care conversations to reduce downstream clinical burdens on specialty palliative care [7<sup>¶</sup>,12]. Specialty palliative teams adapted services by being integrated at the point of care (e.g., emergency department, outpatient oncology clinic) [9<sup>¶</sup>,10<sup>¶¶</sup>], expanding teleconsultation services to 24/7 smartphone delivery

[8<sup>¶</sup>], and providing a ‘mobile palliative care team’ to address psychological and spiritual needs [11<sup>¶¶</sup>]. Specialty palliative care teams also conducted training for generalist providers to enhance primary palliative care capabilities [10<sup>¶¶</sup>,13<sup>¶¶</sup>].

Perhaps the most significant change in this domain was the new – or enhanced – utilization of telehealth-supported clinical encounters (phone- or video-based) and electronic patient portals [8<sup>¶</sup>,9<sup>¶</sup>,11<sup>¶¶</sup>,14,15,16<sup>¶</sup>–19<sup>¶</sup>]. These interventions were critical in bridging care delivery gaps imposed by COVID-19 mitigation (e.g., social distancing, visitor restrictions). Although patients and their caregivers demonstrated comfort [16<sup>¶</sup>] and satisfaction [8<sup>¶</sup>,11<sup>¶¶</sup>,18<sup>¶</sup>] with telehealth, these approaches were not considered interchangeable with in-person care by patients, caregivers, and healthcare providers alike [16<sup>¶</sup>–19<sup>¶</sup>]. For example, outpatient telehealth visits were not well received by patients with cancer newly referred to home-based palliative care, owing to the lack of an initial in-person home-based assessment [19<sup>¶</sup>]. Patients also reported that electronic patient portals were only helpful to the extent that providers responded promptly [18<sup>¶</sup>]. Healthcare providers lacked formal training in telehealth delivery [15], which led to challenges in navigating communication barriers [17<sup>¶</sup>], establishing therapeutic relationships, and developing the plan of care [9<sup>¶</sup>,18<sup>¶</sup>,19<sup>¶</sup>]. The lack of in-person assessments required extra time and expert communication skills to navigate patient/caregiver concerns adequately [18<sup>¶</sup>].

### Domain 2: physical aspects of care

The pandemic presented new challenges in maintaining high-quality physical symptom management. Breathlessness and agitation/delirium were seen with increased frequency among inpatients [17<sup>¶</sup>,20<sup>¶¶</sup>], yet were difficult to manage given the novelty of the virus and the often-added complication of the immunocompromised states of patients with cancer. Symptom management tools were developed to navigate complex COVID-related symptoms [21]. In outpatient settings, changing patterns of care led to variable access to symptom information [16<sup>¶</sup>,22,23], making it difficult for patients to disentangle COVID-related versus cancer-related symptom concerns [16<sup>¶</sup>]. The brevity of telehealth visits with oncology providers sometimes prevented comprehensive symptom assessments [18<sup>¶</sup>]. Thus, there was broad uptake of phone-facilitated specialty palliative care consultation services by patients with cancer to address uncontrolled symptoms (64% of calls) [8<sup>¶</sup>].

- I. Structure and Processes of Care**  
*Palliative care structure and delivery may vary based on setting, but can be delivered in any healthcare setting. Common components include an interdisciplinary team providing comprehensive assessment to develop a palliative care plan whilst coordinating care and transitions. Additionally, the interdisciplinary team requires cross-discipline education and emotional support to promote resilience and sustainability.*
- II. Physical Aspects of Care**  
*Palliative care interdisciplinary teams aim to screen, assess, treat, and relieve physical symptoms and improve functional status through nonpharmacologic and pharmacologic therapies that are in line with the patient's goals-of-care.*
- III. Psychological and Psychiatric Aspects of Care**  
*Palliative care interdisciplinary teams aim to collaborate too screen, assess, and treat psychological and psychiatric aspects of care through providing emotional support and in consultation with psychological and psychiatric services as appropriate.*
- IV. Social Aspects of Care**  
*Palliative care interdisciplinary teams which should include a professional social worker, address social aspects of care, that is social determinants of health and environmental factors, through screening, assessment, and treatment in partnership with patient and families.*
- V. Spiritual, Religious, and Existential Aspects of Care**  
*Palliative care interdisciplinary teams screen and assess each patient and family's individual spiritual history and existential needs on an ongoing basis. Spiritual beliefs and practices are respected and supported; preferences spiritual care providers are consulted as needed.*
- VI. Cultural Aspects of Care**  
*Palliative care interdisciplinary teams provide culturally sensitive, unbiased care for patients regardless of race, ethnicity, language, gender identity, gender expression, sexual orientation, immigration status, social class, religion, physical appearance, and abilities. Teams aim to communicate in patient preferred language, screen for cultural preferences, and develop culturally sensitive individualized plans. Palliative care professionals engage in ongoing reflection to identify biases.*
- VII. Care of the Patient Nearing the End-of-Life**  
*Palliative care teams support patients with specialized end of life care to promote comfort at the end-of-life through aggressive symptom management. Palliative care specialists are charged with educating colleagues on end-of-life care and support caregivers throughout the dying process. Additionally, assesses and provides family and team bereavement needs.*
- VIII. Ethical and Legal Aspects of Care**  
*Palliative care interdisciplinary teams are obligated to be familiar with ethical and legal principles in order to honor patient preferences and provide just care.*

**FIGURE 1.** Domains of high-quality palliative care<sup>a</sup>. <sup>a</sup>Data from National Consensus Project for Quality Palliative Care. Clinical Practice Guidelines for Quality Palliative Care, 4th edition. Richmond, VA: National Coalition for Hospice and Palliative Care; 2018. <https://www.nationalcoalitionhpc.org/ncp>.

### **Domains 3 and 5: psychological/psychiatric and spiritual/religious/existential aspects of care**

We integrated results from these two domains for parsimony, given the frequently interrelated psychological and spiritual findings across articles. Patients, caregivers, and healthcare providers each experienced increased needs for psychological and spiritual supports during the pandemic, yet, reported suboptimal availability of these services, particularly in end-of-life circumstances [20<sup>11</sup>]. Caregivers specifically desired more proactive mental health supports [24<sup>11</sup>]. To address deficiencies, one specialty palliative care team leveraged the expertise of their chaplain and psychologist to offer telehealth to hospitalized patients and their caregivers with psychological and spiritual needs [11<sup>11</sup>]. Caregivers heavily utilized psychological supports, where most sessions (60%) addressed withdrawing/withholding life-sustaining treatments [11<sup>11</sup>]. Conversely, patients more frequently used spiritual supports, where most sessions (74%) addressed spiritual suffering [11<sup>11</sup>].

The mental health crisis stemming from providing care during COVID-19 has been dubbed a ‘second pandemic’ [25], where an estimated 31–53% of healthcare providers have reported distress, anxiety, or depression in varying degrees [24<sup>11</sup>,26], with nurses experiencing greater risk for these outcomes [27,28]. These estimates constitute a significant increase in psychological morbidity among healthcare providers from prior to the pandemic [28,29], and may stem from the demands of providing frequent end-of-life care [15,30], as well as moral distress over the inability to provide optimal care amid COVID-19 mitigation [31<sup>11</sup>,32<sup>11</sup>]. Although many efforts were made to address healthcare providers’ mental health during the pandemic, more comprehensive approaches are needed to adequately address the problem [29,33]. This includes not only expanding access to mental health resources and services but also providing tools to help healthcare providers recognize symptoms and encourage their engagement [33]. Further, these efforts were not typically developed with sustainability beyond the pandemic in mind, leaving additional gaps in addressing mental health problems among healthcare providers long-term, regardless of the cause [33].

### **Domain 4: social aspects of care**

Earlier discharges became more frequent during the pandemic to address hospital capacity issues. These discharges contributed to higher outpatient demands [19<sup>11</sup>], impacting the social needs of patients and their caregivers [24<sup>11</sup>]. Patients reported the unavailability of community-based resources,

such as peer cancer support programs [18<sup>11</sup>]. Although some programs were offered virtually [18<sup>11</sup>,34], patients felt these interactions were not as meaningful as in-person [18<sup>11</sup>]. However, the pandemic-imposed social isolation made virtual support programs desirable over none, particularly among adolescent and young adult patients with cancer [34]. Social isolation compounded the psychological morbidity of patients/caregivers [24<sup>11</sup>], most significantly for bereaved caregivers [35]. Caregivers also felt excluded from patients’ healthcare providers owing to COVID-19 mitigation. They lamented the challenges of receiving second-hand information and the inability to advocate in person for their loved ones [24<sup>11</sup>].

### **Domain 7: care of the patient nearing the end-of-life**

Limitations during the pandemic negatively impacted end-of-life care experiences for patients/caregivers [20<sup>11</sup>,36]. Telehealth-supported inpatient care toward the end-of-life (e.g., WhatsApp-facilitated clinical rounds, Skype/Zoom video calls), while valued, failed to replace caregivers’ physical presence [37], and these technology-supported interventions were inconsistently available [36]. Healthcare providers reported that visitor restrictions hampered end-of-life conversations [30], and caregivers consequently expressed the need for more empathetic, proactive communication from healthcare providers regarding end-of-life decision-making [36]. Bereaved caregivers recounted the emotional toll of not being physically present to say goodbye. Even when exceptions were made [38], the patient’s condition had often deteriorated beyond the point of meaningful interaction [36,37]. Further, up to 51% of palliative care programs lack formalized bereavement support for caregivers in adult settings [39] and 37% in pediatric settings [31<sup>11</sup>]. Even some hospice programs were forced to cancel bereavement services [40<sup>11</sup>].

### **Domain 8: ethical and legal aspects of care**

Findings in this domain comprised a renewed emphasis on advance care planning (ACP) and targeted communication about goals-of-care to facilitate healthcare decision-making. Proactive ACP conversations became a clinical imperative in providing surrogate decision-makers and the healthcare team the anticipatory guidance needed to inform decision-making in the event of patient incapacity [9<sup>11</sup>,41<sup>11</sup>], and nurses were central in helping patients articulate values/preferences in advance [12,42]. However, these conversations were met with new challenges during the pandemic – ethical concerns surfaced over the shortened timeframe to conduct ACP, the lack of



continuity of inpatient healthcare providers to facilitate ACP, and the inability to perform conversations in person [42]. Further, COVID-19 mitigation challenged the traditional physical requirements for ACP documentation (e.g., use of a notary), ultimately delaying completion [12]. Thus, telehealth-facilitated ACP solutions served as a significant policy shift and essential care delivery change in upstreaming ACP before health crises occurred, and electronic systems were leveraged to ensure the documents were available [12]. As patients' prognoses worsened, the majority (60%) of specialty palliative care consultations during the pandemic were used to address targeted goals-of-care conversations with surrogates that accounted for individualized risk–benefit assessments to inform decision-making [43], mainly when patient/caregiver goals appeared misaligned with prognosis [10<sup>11</sup>].

## DISCUSSION

COVID-19 compelled healthcare systems to rapidly modify palliative care delivery to meet the emerging needs of patients with cancer and their caregivers. Although most of the domains of high-quality palliative care delivery were impacted, Domain 6 (cultural aspects of care) was not discretely addressed. Half ( $n = 19$ , 51%) of the studies informing this rapid review were conducted globally and the remaining in the United States and Canada. Despite these diverse locales, the palliative care delivery changes did not greatly differ based on study location – suggesting the changes addressed a unifying set of prioritized palliative care needs that cut across cultures. Implications for the future of palliative care delivery supported by oncology nurses emerged in three areas: first, telehealth; second, psychosocial supports; and third, ACP.

### Telehealth

The first implication – which primarily concerns Domain 1 (structure and processes of care) – champions the routine use of telehealth in supporting palliative care delivery across the cancer continuum. Telehealth serves as a critical tool for scaling palliative care delivery and access – linking patients/caregivers to palliative care services directly from home while continuing disease-directed therapies – which also has the potential to address cancer care disparities [10<sup>11</sup>,44,45]. The review also highlighted telehealth's specific role in facilitating primary palliative care through symptom management, supportive oncology service delivery, and proactive ACP.

To embed telehealth approaches in clinical care long-term, continued systems-level support is

imperative. Institutional commitment to the required staffing, clinical space, clinical workflow, and patient/caregiver access are needed [12]. Oncology nurses are well suited to fill staffing needs for providing telehealth-facilitated primary palliative care. Evidence indicates that oncology nurses have previously guided patients with advanced cancer in symptom management [46] and cancer survivors in functional performance improvements using telehealth [47]. Digital equity must also be considered with respect to patient/caregiver access. For instance, patients living in rural areas or who lack the socioeconomic means to afford the necessary technologies must be assured pathways to expert care. Telehealth best practices include ensuring a user-centered design, establishing rapport, setting the agenda, responding empathically to emotions, delivering information, and effectively ending the visit [48]. However, more rigorous testing is needed. Meaningful lines of inquiry moving forward include evaluating algorithms to identify which patients would benefit from telehealth, examining technological literacy, assessing the quality of communication in telehealth encounters, testing telehealth encounter efficacy in varied contexts (e.g., cultural or clinical), and investigating patient/caregiver perceived quality of care experience [9<sup>10</sup>,10<sup>11</sup>,11<sup>12</sup>,14,48–50].

### Psychosocial supports

Continuity of care emerged as a challenge during the pandemic, where palliative and oncology teams had the opportunity to fully appreciate the role that wrap-around social, psychological, and spiritual support services (Domains 3–5) played in the quality of patient and caregiver experiences when they were no longer easy to access or available. Other evidence also indicates that patients with cancer and their caregivers often cannot access supportive services physically housed within cancer centers, owing to transportation or scheduling conflicts, thus, preferring community-based supports closer to home [51,52]. As cancer care is increasingly moving outpatient, stronger practice-community partnerships are needed, including streamlined processes to connect patients/caregivers to community partners between clinic visits. This review underscored the value of electronic patient portals in facilitating such efforts, where 'support bundles' with information about available supports were identified as a simple low-touch solution in connecting patients/caregivers to these services [18<sup>19</sup>]. Prior evidence supports the role of nurse-led transitional care models in improving the continuity of care across healthcare settings among older adults with chronic conditions [53]. By

extension, oncology nurses may also find adapted transitional care models useful in providing higher-touch continuity solutions for community-based supportive services across the cancer continuum. These proactive approaches to address supportive oncology needs through primary palliative care may also help reduce demands on already overburdened specialty palliative care programs.

The dearth of psychological support services available for caregivers, especially during bereavement (Domain 7), as well as for healthcare providers, came to the fore during the pandemic (Domain 1). Palliative care programs need to develop more formalized bereavement programs, which may take creative solutions, such as telehealth, to adequately extend bereavement programs [31<sup>■</sup>,54]. Although not a new phenomenon to providers, the pandemic has made healthcare systems and the public acutely aware of the moral and psychological distress healthcare providers experience and the ultimate impact on their mental health. Many clinicians experienced mental health impacts to such an extent that they contemplated leaving the healthcare profession altogether [28,55], a phenomenon disproportionately impacting nurses [28]. And yet, comprehensive mental health supports for healthcare providers are nascent. This pervasive gap warrants healthcare systems to solidify and augment the mental health supportive services made available during the pandemic, including monitoring of psychological morbidity, in-person and/or virtual psychotherapy, resilience and mindfulness psychoeducation, and debriefing and stress management tools [27,29,32<sup>■</sup>,39,56]. These interventions should be coupled with system-wide investments and policies to protect the nursing workforce and prioritize their sustainment long after the consequences of the pandemic [57].

### **Advance care planning**

Early facilitation of ACP conversations (Domain 8) was critical to ensuring patient-centered care in the event of a crisis throughout the pandemic. In hospital settings, nurses are well poised to identify ‘red flag’ interactions during routine care (e.g., patient/caregiver misunderstanding of the treatment intent), which provide opportune moments to conduct further targeted goals-of-care conversations with the primary palliative care team (plus or minus palliative care specialists) [58]. However, inpatient clinical workflow does not always allow nurses to implement these conversations in a high-quality way, suggesting the need for new nurse-led models of ACP delivery in the inpatient setting [59]. In the outpatient setting, nurse-led telehealth

interventions to address symptom concerns among patients with cancer have been effective [46], suggesting the potential benefit of similar oncology nurse-led telehealth-facilitated ACP conversations to address values/preferences for care proactively. Oncology nurses must reclaim and leverage their role in ACP facilitation across the cancer continuum. Patients and caregivers may, now more than ever, be receptive to these conversations due to increased social consciousness around the importance of these conversations ushered in by the pandemic.

### **LIMITATIONS**

Studies in this review were conducted in rapid response to the pandemic to address public health emergency needs and thus, included untested interventions and unvalidated survey measures, leaving concerns over the quality of the evidence. However, these approaches reflect similar methods employed in pragmatic trials, where interventions are developed and conducted under ‘real-life’ conditions. In this way, these synthesized findings may be more translatable and sustainable in practice over time.

### **CONCLUSION**

The current rapid review highlighted critical changes in the current design of palliative care for patients with cancer and their caregivers during the COVID-19 pandemic, which hold significance for assuring high-quality primary palliative care as the pandemic evolves to endemic status. Healthcare systems must continue to invest in their capacity to provide primary palliative care to patients with cancer and their caregivers through leveraging the oncology nursing workforce and telehealth. Our findings reaffirm the need for enhanced clinical workflows that proactively connect patients/caregivers to holistic psychosocial community-based supports. Healthcare providers, in turn, require more formalized psychosocial supports within healthcare systems to address their psychological burdens of providing care. Finally, primary palliative care approaches used to proactively address ACP early in the cancer continuum during the pandemic need to be codified in clinical practice. Oncology nurses are well positioned to continue to support primary palliative care for patients with cancer and their caregivers beyond the pandemic through evidence-based, palliative care practice enhancements across the cancer continuum.

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## Conflicts of interest

There are no conflicts of interest.

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