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INVITED COMMENTARY

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Same storm, different boat: The global impact of COVID-19 on palliative care

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Abstract

Objective: The COVID-19 pandemic has had a complex and profound impact on the provision of palliative care globally. To support learning from palliative care providers and researchers worldwide, the Education Subcommittee of International Psycho-Oncology Society (IPOS) Palliative Care Special Interest Group developed a webinar with presentations by and discussion with eight international palliative care leaders.

Methods: Presentations were content rich; the speakers used both quantitative (e.g., sharing recent statistical findings) and qualitative (e.g., narrative storytelling, anecdotal experiences) approaches to portray the effect of COVID-19 in their region. Subsequent to the webinar, the committee collectively identified five themes conveyed by the presenters through consensus.

Results: The themes included: (1) altered accessibility to palliative care, with socioeconomic status impacting virtual health availability; (2) reduced opportunities to preserve dignity, as survival has been prioritized over preserving the humanity of patients and their loved ones; (3) complicated grief and bereavement arising from social distancing requirements; (4) greater awareness of the importance of sustaining health provider well-being; and (5) the development of valuable innovations across nations, institutions, disciplines, and communities.

Conclusions: Overall, the webinar facilitated valuable connection for global learning and identified opportunities for research and clinical interventions. In an ongoing crisis that has exacerbated isolation, we will need to continue to learn and lean on one another as a global community to navigate ongoing challenges of the COVID-19 pandemic.

KEYWORDS
accessibility, cancer, COVID-19, dignity, end-of-life, global, inequities, LMIC, oncology, palliative care

1 | INTRODUCTION

The COVID-19 pandemic has had, and continues to have, a profound impact on individuals, families, and communities throughout the world. Since 2020 to the time of writing, over 450 million people have been infected and nearly 6 million have died worldwide (see Table 1).[1] In both developed and developing countries, the global pandemic has altered healthcare delivery for medical, surgical, and psychiatric care as well as the death and dying processes for patients, families, and healthcare providers.[2–3] Throughout these challenging times, palliative care teams have played an essential role in alleviating suffering and maintaining quality of life for those with COVID-19 and other life-altering, life-limiting illnesses.[4]

The impact of the COVID-19 pandemic on cancer care globally has been significant. A recent WHO statement suggested that up to 50% of cancer services were disrupted by the pandemic (in countries that participated in the Global Pulse Survey).[5] Many aspects of cancer care, including diagnosis, treatment, and cancer research were initially deprioritized in the face of the pandemic.[6–9] Additionally, palliative care for people with cancer was significantly impacted, resulting in hospital visit restrictions for patients and families, redeployment of staff, reduced resources, and increased workloads.[10] This compelled palliative care teams to look for innovative solutions, such as introducing alternative methods of communication, rapid development of guidelines, and building flexibility into services.[10,11] Inevitably, the pandemic has highlighted the global disparities in cancer care and cancer research, with the Low and Middle Income Countries (LMICs) affected disproportionately.[12]

Given the global impact of the pandemic and the multitude of ways in which palliative care providers have responded to the ongoing crisis, the International Psycho-Oncology Society's (IPOS) Palliative Care Special Interest Group (SIG) Education Subcommittee created an opportunity for collaborative learning through an online webinar. In this webinar, an international panel of palliative care leaders from eight different regions of the world (see Table 1) deliberated on the impact of the COVID-19 pandemic in their country and participated in a discussion that examined some of the unique and shared experiences of palliative care patients, families, and providers. Issues such as palliative care practice, resource management, end-of-life practices, grief, dying alone, and provider fatigue and resilience were explored. This commentary aims to summarize the key challenges and opportunities raised by these experts in order to illustrate the impact of the COVID-19 pandemic on palliative care service delivery in the global context. Overarching themes were generated through an informal, iterative process, such that committee members discussed themes at each biweekly meeting, re-watching the webinar in-between as necessary, until consensus was reached. The identified themes centered on the following: changes in accessibility; preservation of human dignity; addressing ubiquitous death, grief, and bereavement; the importance of supporting providers; and the need for rapid innovation in palliative care (see Table 2).

2 | IDENTIFIED THEMES

2.1 | Access to palliative care

One of the most profound ways in which the pandemic has affected palliative care practice relates to the ways in which patients and families have accessed needed care and the ways in which this care has been provided. Throughout the world, a range of quarantine and social distancing measures have been implemented to curb the transmission of the virus.[13] The need for social distancing resulted in greater reliance on technology to create and maintain connections with patients, families, and each other.[14] The rapid transition to telehealth enabled many palliative care patients to receive ongoing, needed care; however, financial and socio-cultural inequities between and within developed and LMICs resulted in uneven access to palliative care services.[15] Many patients were required to make difficult decisions regarding their care, weighing a risky visit to the hospital against staying at home without medical attention.[14] Governmental lockdowns prevented travel from rural communities to urban areas, where medical services are often localized.[16] Hospitals were overwhelmed and often understaffed.[14] Dr. Mevhibe Hocaoglu, Research Associate from King's College London, indicated that more people in the UK had died at home without the supportive services offered by palliative care.[17]

TABLE 1 Information regarding the webinar's speakers

Presenter name	Country	Role/Institution	Total covid cases[a]	Total covid deaths[a]
Lili Tang, M.D.	China	Director, Psycho-Oncology Peking university Cancer Hospital President, Chinese Psycho-Oncology Society	761,907	9482
Mevhibe Hocaoglu, Ph.D.	United Kingdom	Research Associate Cicely Saunders Institute of Palliative Care Policy and Rehabilitation, King's College London	19,530,489	162,738
Jennifer Kapo, M.D.	United States	Director, Palliative Medicine Yale Cancer Center Yale School of Medicine	78,777,620	960,144
Isabel Centeno, M.Ed.	Mexico	Psycho-Oncologist, Zambrano Hellion Hospital Board Member, Elizabeth Kübler-Ross Foundation	5,605,636	321,054
M. R. Rajagopal, M.D.	India	Chairman, Pallium India Director, Trivandrum Institute of Palliative Sciences	42,993,494	515,877
Miriam Mutebi, M.D.	Kenya	Assistant Professor of Surgery, Medical College, Aga Khan university Chair, Kenya Society of Hematology and Oncology	323,183	5645
Jennifer Philip, M.D.	Australia	Chair of Palliative Medicine, University of Melbourne, Peter MacCullum Cancer Centre, Royal Melbourne Hospital	3,193,065	5586
Harvey Max Chochinov, M.D. Ph.D.	Canada	Distinguished Professor of Psychiatry, University of Manitoba Senior Scientist, CancerCare Manitoba Research Institute	3,349,647	37,229

[a]Data from World Health Organization COVID-19 Dashboard, accessed 3/15/22.

Nevertheless, speakers from the webinar also noted some improvements to accessibility in certain parts of the world. The rapid shift to telemedicine in developed countries and some LMICs allowed for longer, safer medical appointments at the comfort and ease of patients' homes.[14] Similarly, more people could receive support than ever before with the advent of virtual prescribing and patient-centered helplines.[14] Dr. M. R. Rajagopal, Chairman of Pallium India, narrated efforts made to reach the masses who faced issues with access to care using community-developed helplines for palliative care and bereavement services. It has become evident that telemedicine has the potential to be a vehicle for excellent care. However, more work is needed to address the inequities caused by a reliance on technology, particularly in developing countries and underserved communities where access to palliative care resources has been extremely limited or non-existent.[15] In the future, palliative care will need to creatively tackle the issue of accessibility, leaning heavily on policy and community support to increase care for all.

2.2 | Dignity

One of the greatest, intangible challenges of the pandemic has been that of patient dignity. Healthcare providers, globally, have struggled to safeguard the dignity of the sick and dying, which is one of the most important goals of end-of-life care.[18] During the webinar, speakers noted that limited visitation hours due to public health restrictions, the absence of loved ones at the time of death, and obstructed communication through layers of personal protective equipment (PPE) have led to patients dying in seclusion, thereby undermining their sense of dignity and increasing depersonalization.[19] Poignantly stated by Dr. Isabel Centeno, Psycho-Oncologist at

TABLE 2 Examples of each identified theme

Theme	Speaker (country)	Example quote
Accessibility	Harvey Max Chochinov (Canada)	*"COVID has been a global experience. We are all in this same storm together… But certainly not in the same boat."*
	Lili Tang (China)	Patient: *"Whether or not if I die from COVID-19 or not, if I stop treatment, I will die from cancer."*
Dignity	Jennifer Kapo (USA)	*"Despite this unimaginable challenge, there were countless examples of compassion, strength, and wonderful medical care."*
	M.R. Rajagopal (India)	*"We cannot distinguish between physical support and psychological support."*
Grief and Bereavement	Isabel Centeno (Mexico)	*"This new narrative about the process of death and dying implies a negative impact on grieving and mean[s] today—and will mean in the future—the appearance of mental disorders that will probably transcend generations."*
	M.R. Rajagopal (India)	*"The extended suffering in LMICs is beyond your imagination. COVID caused tremendous grief."*
Support of Healthcare Providers	Jennifer Philip (Australia)	Provider: *"I felt powerless. I couldn't* save *her, and I couldn't help them."*
	Mevhibe Hocaoglu (UK)	*"We have seen that they have suffered from moral distress, but, of course, not moral distress from the humongous amount of death. Palliative care providers are trained to deal with death; we noticed that [the moral distress] was more due to not being able to provide the standard-of-care that they wished."*
Innovation	Miriam Mutebi (Kenya)	*"The pandemic offers us a silver lining opportunity to rethink how to deliver [palliative care] services to our populations."*
	Mevhibe Hocaoglu (UK)	*"Palliative care services have been very flexible and very responsive in response to the pandemic, introducing—what we call- frugal innovations. They have overcome quite a number of barriers."*

Zambrano Hellion Hospital in Mexico, at the height of the pandemic, survival was often prioritized over humanity.

Even as the pandemic continues to threaten personhood, there were many heroic accounts of medical providers' and community members' tireless efforts to preserve the dignity of the sick and dying, reminding us that crises can often lead to profound acts of compassion and displays of pro-social behaviour.[20] For example, in India, a community rallied around a woman with cancer, in intense pain, and forced to quarantine in an impoverished environment, with the physician providing her with morphine outside of his working hours and two social workers delivering a mattress for increased comfort. In another example, Dr. Lili Tang, Director of Psycho-Oncology at Peking University Cancer Hospital, shared a photograph of a medical provider and his elderly patient admiring the sunset outside the confines of their hospital room. Stories such as these remind us that how we die matters and emphasizes the essential role of palliative care in restoring human dignity during humanitarian crises like the pandemic.[21] Indeed, as stated by Dr. Rajagopal, "we cannot distinguish between physical support and psychological support."

2.3 | Grief and bereavement

Another theme that emerged revolved around ubiquitous death, grief, and bereavement. The pandemic has precipitated a series of losses, both individually and collectively.[22] We have lost our sense of safety, livelihoods, lives, and loved ones.[22,23] Deaths have been dehumanized, often occurring in isolation, with infection control protocols restricting access of family members. In this way, the pandemic has amplified suffering, putting the world at risk of complicated grief and bereavement.[24] Deaths due to COVID-19 have often been sudden and catastrophic, accompanied by much pain and suffering, clothed in uncertainty.[25]

Yet the pandemic has impacted not merely those who have lost a loved one to COVID-19, but all people who lost a loved one in the recent past, even to non-COVID-related illnesses.[26] First, family members are unable to witness the medical care provided, say their final goodbyes, or pay their last respects to their dying loved ones.[22] Myriad images exist of healthcare providers holding up a smart phone to the patient as families say their final goodbyes virtually.[27] The residual trauma of this disconnection makes processing losses difficult, and families may wonder about their loved one's final moments and suffering.[28] Additionally, after a person's passing, the pandemic has prohibited traditional, communal rituals of mourning.[28] As Dr. Centeno explained, joyful funeral celebrations with mariachis in Mexico have been replaced with austere images of pallbearers dressed in PPE. In Canada, some have attended "virtual funerals" to increase connection. Social isolation and lack of socio-emotional support, financial concerns, and fear for one's own safety further complicates the mourning process, increasing the risk of psychological morbidity in the bereaved family members.[25] Even after the crisis of the pandemic passes, many will still confront the extended suffering of those left behind, as traumatic loss and unresolved grief may, as noted by Dr. Centeno, "transcend generations."

2.4 | Support of healthcare providers

Provider fatigue and burnout was another important theme that emerged in the webinar and continues to be a pressing issue today. Palliative care clinicians have been leaders in caring for other providers while also tending to their patients' suffering.[29,30] In early stages of the pandemic, palliative care providers in the UK felt both overwhelmed and overlooked, in that while they were providing essential end-of-life care, they were not recognized as frontline workers.[31] Additionally, many speakers mentioned the moral distress experienced by providers when they felt either helpless or responsible for patient suffering. For example, Dr. Jennifer Philips, Chair of Palliative Medicine at the University of Melbourne, described how an Australian provider felt "powerless" as she was unable to alleviate suffering in a family that had displaced their frustration and anger to the healthcare team. Recent findings suggest that difficulties in communication, visitor restriction policies, and resource constraints also contribute to feelings of helplessness and moral injury among healthcare staff,[32] and each of these concerns were affirmed by the speakers as sources of stress for providers. Shortage of PPE, staff shortages, overwork and exhaustion, and fear for safety of self and loved ones also contributed to burnout among healthcare staff.[33]

In order to adequately support healthcare workers in palliative care and beyond, both material and psycho-spiritual needs must be addressed. Examples of staff support, such as Yale's *Caring for Ourselves* initiative in the United States, were effective in addressing problems at the individual, team, and institutional levels.[34,35] Community initiatives may also help alleviate provider burnout, such as demonstrated throughout India and Kenya, where community members stepped up to provide much needed palliative services to those suffering in their homes. Overall, whether palliative care was an established or emerging field in their respective country, each speaker emphasized the need for integrating palliative and end-of-life care into the pandemic response, reaffirming the importance of the palliative care provider. However, the speakers also reiterated the need to enhance support and provide unified access to resources to sustain the work of palliative care providers in this ongoing crisis.

2.5 | Innovation

In the face of these significant challenges, the intense stress of the pandemic has served as a crucible for rapid, "frugal" healthcare innovations.[36] Given the dearth of resources, many of these innovations required increased flexibility, effective communication, interdisciplinary collaboration, and strong leadership. Our speakers provided many examples of such novel developments, including collaborative task forces, interdisciplinary training, new technology, and safety monitoring protocols. For instance, in the United States at Yale, an ethics advisory committee was constituted, and institution-wide communication skills training was implemented to proactively prepare for the possibility of ventilator shortages and crisis decision-making.[37] Palliative care providers in India uniquely leveraged the support of their community, providing virtual training to local students in order to reach those in inaccessible, critical containment zones.[38] Regardless of the type of innovation, Dr. Rajagopal described the pandemic as a "cruel, but great teacher," highlighting the ways in which the field has grown in order to adapt to the ongoing crisis. Similarly, Dr. Miriam Mutebi, Assistant Professor of Surgery at Aga Khan University in Kenya, noted that the pandemic offered us a "silver lining opportunity" to rethink how we deliver services to our communities. With careful reflection, there will likely be some innovations that the field retains and others that will still need further consideration and evidence before becoming standard of care.

3 | CONCLUSION

We add to the pre-existing, important conversations regarding the impact of COVID-19 by shining a light on the global challenges faced by palliative care professionals. The webinar made space for a global community of health professionals to reflect together on how the pandemic has challenged palliative care services locally and globally.[39] Importantly, this webinar highlighted the commonality of experiences across countries of varying socioeconomic and cultural backgrounds, reiterating the universal impact of the pandemic. It also showcased the unique challenges and innovations across regions, highlighting global inequities and the creative, translatable, and practical solutions that have emerged. Given the ongoing nature of the pandemic, new crisis situations are likely to emerge. The ability to innovate and adapt to local exigencies has the potential to transform the scope and reach of palliative care worldwide. We look forward to continued conversations on the central themes highlighted in the webinar, that of accessibility, dignity, grief, provider support, and innovation. It is only by continuing to learn and lean on one another will we, as palliative care clinicians and scientists across the globe, be able to continue to navigate the challenges associated with the pandemic and beyond.

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CONFLICTS OF INTEREST

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DATA AVAILABILITY STATEMENT

Data sharing not applicable to this article as no datasets were generated or analysed during the current study.

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