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The inaugural United States World Hospice and Palliative Care Day Celebration: A virtual coming together

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Abstract

Objective. On October 10, 2020, the Memorial Sloan Kettering Cancer Center Supportive Care Service hosted their first-ever United States (US) World Hospice and Palliative Care Day (WHPCD) Celebration. The purpose of this article is to describe the US inaugural event in alignment with the broader goals of WHPCD and provide lessons learned in anticipation of the second annual conference to be held on October 5–6, 2021.

Methods. Description of the inaugural event in the context of COVID-19 and WHPCD, co-planning conference team reflection, and attendee survey responses.

Results. The Worldwide Hospice Palliative Care Alliance initially launched WHPCD in 2005 as an annual unified day of action to celebrate and support hospice and palliative care around the world. The US-based innovative virtual conference featured 23 interprofessional hospice and palliative care specialists and patient and family caregiver speakers across nine diverse sessions addressing priorities at the intersection of COVID-19, social injustice, and the global burden of serious health-related suffering. Two primary aims guided the event: community building and wisdom sharing. Nearly 270 registrants from at least 16 countries and one dozen states across the US joined the free program focused on both personal and professional development.

Significance of results. Unlike many other academic conferences and professional gatherings that were relegated to online forums due to pandemic-related restrictions, the US WHPCD Celebration was intentionally established to create a virtual coming together for collective reflection on the barriers and facilitators of palliative care delivery amid vast societal change. The goal to ensure a globally relevant and culturally inclusive agenda will continue to draw increased participation at an international level during future annual events. Finally, the transparent and respectful sharing of palliative care team experiences in the year preceding the conference established a safe environment for both individual expression and scholarly discussion.

On October 10, 2020, the Memorial Sloan Kettering (MSK) Cancer Center Supportive Care Service hosted their first-ever United States (US) World Hospice and Palliative Care Day (WHPCD) Celebration (2020). The innovative virtual conference forum brought together a diverse, international cadre of interprofessional hospice and palliative care clinical experts, researchers, policy advocates, and organizational leaders with two primary aims in mind: community building and wisdom sharing. Nearly 270 registrants from at least 15 countries joined the program free of cost to address critical issues impacting the field at the intersection of three global and urgent public health crises: the COVID-19 pandemic, social injustice, and serious health-related suffering. Opening and closing keynotes, rapid-fire talks and panel discussions, patient and family caregiver reflections, and audience interaction all contributed to a personally and professionally gratifying experience for presenters and participants alike. The purpose of this special report is to describe the US inaugural event in alignment with the broader goals of WHPCD and provide lessons learned in anticipation of the second annual conference to be held on October 5–6, 2021.

COVID-19 has motivated health workers to create new modes of sharing experiences and learnings to optimize care quality in myriad contexts during this public health emergency. Individuals and organizations working in hospice and palliative care fields have come together across borders throughout the pandemic to provide globally relevant resources for

interprofessional stakeholders (Center to Advance Palliative Care, CAPC, <https://www.capc.org/covid-19/>; End-of-Life Nursing Education Consortium, ELNEC, <https://www.aacnursing.org/ELNEC/COVID-19>; National Hospice and Palliative Care Organization, NHPCO, <https://www.nhpco.org/coronavirus>). For example, from April through June 2020, the International Children's Palliative Care Network (ICPCN), International Association for Hospice and Palliative Care (IAHPC), Palliative Care in Humanitarian Aid Situations and Emergencies network (PalCHASE), and Worldwide Hospice Palliative Care Alliance (WHPCA) recruited 127 experts from 24 countries to create the *Global Palliative Care and COVID-19 Series Briefing Notes* with recommendations for United Nations member states and civil society organizations to promote palliative care access during the SARS-CoV-2 public health crisis (De Lima et al., 2020). COVID-19 has also required individuals and groups across disciplines and systems providing health and social care to use virtual conference forums to share evidence, disseminate best practices, and provide networking opportunities (Sethi et al., 2020). The inaugural 2020 US WHPCD Celebration leveraged global academic–practice relationships and partnerships as well as the virtual platform to provide a day of reflection on our shared palliative care efforts and advance the art and science of the field.

World Hospice and Palliative Care Day

WHPCD is a unified day of action to celebrate and support hospice and palliative care around the world (WHPCA, 2020a). The first WHPCD was in 2005 and has been celebrated every year since on the second Saturday each October. Voices for Hospices is a wave of concerts taking place on WHPCD every 2 years. Events are held throughout the world in order to highlight the importance of palliative care in every country. Each year a different theme is chosen to highlight an important aspect of palliative care. Recent themes included: “My Care, My Right” (WHPCA, 2019); “Because I Matter” (WHPCA, 2018); “Don't Leave Those Suffering Behind” (WHPCA, 2017); and “Living & Dying in Pain: It Doesn't Have to Happen” (WHPCA, 2016). The 2020 WHPCD theme was “My Care, My Comfort” (WHPCA, 2020b; Table 1). Most years, between 150 and 200 events are held in around 70 countries worldwide and are tracked on the WHPCA website, making WHPCD one of the most successful world health days. The aims of the annual WHPCD are to:

- Share WHPCA's vision to increase the availability of hospice and palliative care throughout the world by creating opportunities to speak about the issues.
- Elevate awareness and understanding of the medical, social, practical, and spiritual needs of people living with a life-limiting illness and their families.
- Raise funds to support and develop hospice and palliative care services around the world (WHPCA, 2020a).

As part of the October 2020 WHPCD, a new second edition of the *Global Atlas of Palliative Care* was released (Connor, 2020). The *Atlas* is published by the WHPCA in collaboration with the World Health Organization. The *Atlas* paints a picture of the state of palliative care worldwide, including needs categorized by disease/condition, the status of palliative care program development by country, associated barriers and gaps to palliative care progress, resources that support and serve as examples of innovative care, and concrete ways forward. Key findings from

Table 1. Key messages of the 2020 WHPCD: “My Care, My Comfort” (WHPCA, 2020b; reprinted from WHPCA with permission)

1. With palliative care, I can access the best standard of **care** and the highest level of **comfort** as I experience a serious health condition.
2. Palliative care ensures caregivers and family members receive the best support to provide **care and comfort** for their loved ones at home or in care facilities.
3. Health workers require the psychological, social and spiritual **care and comfort** that comes with palliative care services and training.
4. To ensure the best **care and comfort** is available to all, palliative care must be mainstreamed into my country's health care system, including through Universal Health Coverage reforms.
5. Palliative care is an essential service to relieve pain and suffering related to COVID-19 and pre-existing health conditions.

The key ask is this:

Show your support for palliative care in building stronger health systems, with palliative care funded and included in Universal Health Coverage.

the *Atlas* included updated estimates of the need for palliative care worldwide (Figure 1). Nearly 57 million patients need palliative care — including over 25 million near the end of life and almost 4 million children — with only 12% of the need being met. Over 75% of those needing care reside in low- and middle-income countries and 64% of countries have no or very limited provision of palliative care. The great majority of those who need palliative care are older and suffering from non-communicable diseases, and 83% of countries have low to non-existent access to internationally controlled essential medicines for pain and symptom relief (Connor, 2020). The *Atlas* is an important advocacy tool for action to address these worldwide unmet needs.

A virtual coming together

The concept for the US day's celebration emerged from Dr. Billy Rosa's nursing, palliative care, and global health background and his desire to honor the work of hospice and palliative care specialists. He partnered closely with nurse practitioner, Shila Pandey, and physician, Andrew Epstein, to create an agenda that would address the most pressing and internationally relevant issues affecting practice. Dr. Judy Nelson, Chief of the MSK Supportive Care Service, provided unwavering support to successfully deliver the event with integrity and quality.

The event was free of cost to promote the highest possible worldwide involvement. It is essential to note that while many academic conferences and gatherings have been restricted to online platforms to promote scholarly exchange throughout the pandemic, the US WHPCD Celebration was intentionally designed as a virtual celebration to interface with an international and culturally diverse audience. Attention was given to creating an agenda that was globally relevant and directly addressed the major societal, health, and palliative care dilemmas of the preceding year. Virtual forums for this event are expected to continue following the likely future return to in-person conferences.

At the start of the day, Dr. Rosa lit a candle over the virtual platform to acknowledge all palliative care colleagues worldwide and the patients and families that we serve. He also asked attendees to take a moment of silence to honor their own individual efforts to treat serious health-related suffering. Felicia Knaul, PhD, MA, Chair of the Lancet Commission on Global Access to Palliative Care and Pain Relief, provided the opening presentation, summarizing key findings of the Lancet Commission report (Knaul et al., 2018). Dr. Knaul addressed international opioid

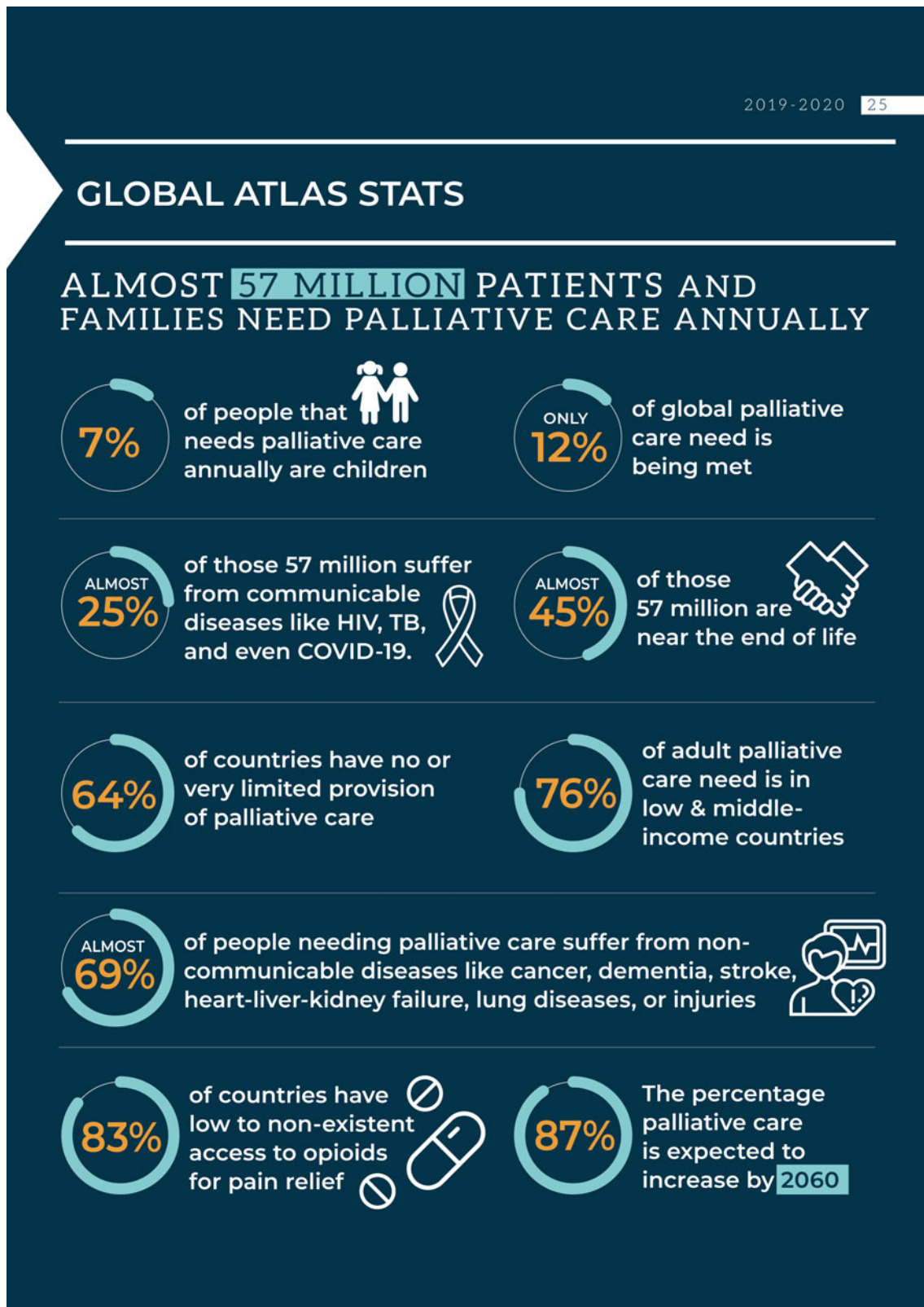


Fig. 1. Global Atlas Stats (Connor, 2020; reprinted from WHPCA with permission).

disparities, including universal access to a cost-effective “Essential Package” of palliative care and pain relief interventions (e.g., immediate-release oral and injectable morphine) to alleviate serious health-related suffering at end of life.

Throughout the day, an impressive range of 23 interprofessional experts and patient/family caregivers provided nine interactive sessions addressing hospice and palliative care during COVID-19. Topics included leadership approaches; equity,

Table 2. US WHPCD conference sessions and topics addressed

Session title	Topics addressed
Global Palliative Care: Where Are We Headed?	<ul style="list-style-type: none"> Lancet Commission Report on Global Access to Palliative Care and Pain Relief key findings and recommendations
Global Exemplar: Pallium India	<ul style="list-style-type: none"> Exemplar case of international collaboration between the US and Pallium India
Patient & Family Conversation	<ul style="list-style-type: none"> “Why Not Me?” A Patient’s & Wife’s Perspectives on Living Well With Advancing Cancer & the “Gift” of Hospice
Hospice & Palliative Care Service Leaders in a Global COVID-19 Hotspot	<ul style="list-style-type: none"> Leadership barriers, facilitators, lessons learned, and recommendations for service, institutional, and organizational levels of hospice and palliative care
Equitable & Inclusive Palliative Care: Social Justice NOW	<ul style="list-style-type: none"> Inclusive hospice and palliative care for lesbian, gay, bisexual, transgender, and queer/questioning (LGBTQ+) individuals and populations; accessible palliative care for rural African-American family caregivers; analgesic and pain disparities; cultural assessment, competence, and humility in palliative care
Palliative Nursing in the COVID-19 Era	<ul style="list-style-type: none"> Palliative nursing leadership in academia and in the clinical setting; palliative nursing research initiatives at the NIH/National Institute of Nursing Research; international palliative nursing education efforts through the End-of-Life Nursing Education Consortium (ELNEC)
The Urgency of Interprofessional Spiritual & Existential Care in the Age of Pandemic	<ul style="list-style-type: none"> Spiritual and existential care assessment, screening, and delivery at generalist and specialist levels in the context of COVID-19 for patients, caregivers, and healthcare workers during an individually and socially distressing crisis
Psychosocial & Ethical Considerations During COVID-19	<ul style="list-style-type: none"> Exemplars, case studies, and recommendations for grief and bereavement, caregiver support, family and couple counseling, and clinical ethics during the acute and chronic phases of COVID-19
Hospice & Palliative Care Advocacy in a New World	<ul style="list-style-type: none"> Palliative care advocacy definitions, priorities, and guidance for advancing palliative care access locally, nationally, and internationally

inclusivity, and social justice; palliative nursing in clinical practice, policy, research, and education; spiritual and existential care; and psychosocial and ethical considerations (Table 2). A rich, compassionate, and deeply moving dialogue with an advanced cancer patient and his wife, entitled “Why Not Me?,” contributed a hopeful perspective on the benefits of hospice and palliative care in improving holistic comfort and psychosocial support in the context of anticipatory grief.

Katherine Pettus, PhD, Advocacy Officer of the IAHP, delivered closing comments on the importance of informed advocacy in local and global forums. With pragmatic guidance for all participants, Dr. Pettus reminded the audience of Sisyphus — the Greek god who cheated death on two occasions and was banished to Hades to futilely push a giant boulder uphill for all eternity. She likened the myth to modern health systems that try to cheat death only to have the boulder of patient, family, and health system needs roll downhill over and over again. Dr. Pettus (2020) suggested that re-envisioning the Sisyphus myth is needed to encourage the “rock of serious health-related suffering” over the hill of sociopolitical and multi-stakeholder indifference.

Community response and future directions

A post-event unpublished evaluation generated 43 responses from a total of 265 invitations sent via e-mail. The evaluation helped us to identify participants from at least 16 countries (Bolivia, Cameroon, Canada, Germany, Ghana, India, Indonesia, Italy, Lebanon, Liberia, Mexico, Nigeria, Palestine, Saudi Arabia, South Africa, and Switzerland) and 12 states across the US. The low response rate (16%) may have been related to the planning team’s inability to provide continuing education credits. However, certificates of attendance were provided for participants to demonstrate professional development activities. Disciplines represented included nurses, nurse practitioners, social workers,

chaplains, physician assistants, physicians, pharmacists, psychologists, integrative medicine practitioners, students, and administrative and research personnel. Attendees hailed from inpatient medical or acute care units, outpatient clinics, long-term care, inpatient and home hospices, inpatient palliative care units, community-based and home care services, and academic and university settings.

The international hospice and palliative care landscape is changing on a daily basis in the face of COVID-19 and severe resource constraints worldwide. The conference planning committee believes that co-creating a safe and supportive global networking space to promote both personal reflection and interprofessional development is imperative to sustaining the field amid the evolving pandemic and widespread social injustice challenges. Both individual expression and scholarly discussion are critical to supporting palliative care teams during these unprecedented times.

The Second Annual US Celebration of WHPCD will be a two-day virtual event to be held on October 5–6, 2021. Although formal and informal feedback following the conference was overwhelmingly positive, there are improvements being made to further improve learner and user outcomes during future events. First, the conference will be broadcast live during alternating morning and evening times to maximize accessibility and convenience for a broad range of time zones. Next, we have expanded and diversified the planning committee to include representation from social work, clinical ethics, pharmacy, chaplaincy, and psychology. Third, we will better optimize the use of breakout technology and virtual platform advancements to promote interprofessional and transnational networking. Finally, we will be providing continuing education credits for attendees and recording the event to promote asynchronous access to conference sessions.

The planning team remains committed to ensuring the program remains cost-free or appropriately subsidized for colleagues

living in low- and middle-income countries to eliminate financial burden and promote cross-cultural connectivity. Our event promotes the attendance, inclusion, and active participation of colleagues from under-resourced world regions who may not otherwise have the opportunity to travel or engage the global palliative care community. We expect these enhancements, as well as a longer lead time to disseminate information about the 2021 event, will significantly increase and broaden participation. Individuals or organizations with questions, recommendations, or interest in our future events should contact the authors of this paper.

Conclusion

During the final moments of the inaugural October 10, 2020 event, Dr. Rosa brought onto screen the candle he had lit at the start of the day to symbolize all participants' dedication to hospice and palliative care and to remember the patients, family caregivers, and communities we serve, as well as the colleagues we partner with in this sacred work. He read an excerpt from "Letter to a Young Activist During Troubled Times" by psychoanalyst, post-trauma specialist, and activist, Clarissa Pinkola Estés (2003–2020), PhD:

"In any dark time, there is a tendency to veer toward fainting over how much is wrong or unended in the world. Do not focus on that ... We are needed, that is all we can know ... One of the most calming and powerful actions you can do to intervene in a stormy world is to stand up and show your soul. Soul on deck shines like gold in dark times ... When a great ship is in harbor and moored, it is safe, there can be no doubt. But ... that is not what great ships are built for."

Perhaps there are no words that better summarize the underlying intention and hope for the US WHPCD Celebration. The virtual coming together merged our art and science in a critical emergent forum to remind each of us that we are needed now more than ever. In fact, it is the building of community and sharing of wisdom that bind and strengthen our collective work to alleviate serious health-related suffering across cultures and contexts. Following the quote by Estés, Dr. Rosa extinguished the candle and concluded the event. With this, an annual global tradition for the field of hospice and palliative care was born.

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