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The 2nd Annual US Celebration of World Hospice and Palliative Care Day: A virtual coming together to support equity in palliative care access

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Abstract

Objective. On October 5–6, 2021, the Memorial Sloan Kettering Cancer Center Supportive Care Service and Department of Psychiatry and Behavioral Sciences hosted the 2nd Annual United States (US) Celebration of World Hospice and Palliative Care Day (WHPCD). The purpose of this article is to describe the event within the broader context of the international WHPCD theme: “Leave No One Behind — Equity in Access to Palliative Care.” We reflect on lessons learned in anticipation of the 3rd annual conference to be held October 3–4, 2022.

Methods. Description of the 2nd annual event, conference planning team reflection, and attendee evaluation responses.

Results. The Worldwide Hospice Palliative Care Alliance launched WHPCD in 2005 as an annual unified day of action to celebrate and support hospice and palliative care around the world. The 2021 US-based innovative virtual conference featured 37 interprofessional hospice and palliative care specialists and patient and family caregiver speakers across 11 diverse sessions with a focus on health equity and COVID-19 considerations. Two primary aims continue to guide the event: community building and wisdom sharing at the intersection of art and science. 278 registrants from at least 14 countries and 21 different states across the US joined the program, which served as a global debriefing for hospice and palliative care workers from diverse settings, contexts, and disciplines.

Significance of results. The US WHPCD Celebration creates a virtual coming together for collective reflection on hospice and palliative care delivery amid vast changes in clinical practice, research, and policy, both locally and globally. In addition, our goal to ensure an internationally relevant, culturally inclusive, and multidisciplinary agenda will continue to draw increased participation worldwide during future annual events.

Introduction

On October 5–6, 2021, the Memorial Sloan Kettering (MSK) Cancer Center Supportive Care Service and Department of Psychiatry and Behavioral Sciences co-sponsored the 2nd Annual US Celebration of World Hospice and Palliative Care Day (WHPCD) (MSK, 2021). Building on the promising outcomes of the inaugural celebration in 2020 (Rosa *et al.*, 2021b), the 2nd annual conference again used a live virtual format and was condensed over two half-days — one in the morning and the other in the afternoon, to increase global access and participation. The 2021 conference program promoted topics relevant to the Worldwide Hospice Palliative Care Alliance (WHPCA, 2021a) theme — *Leave No One Behind: Equity in Access to Palliative Care* (Figure 1). We aim to provide a brief report of the 2021 event to reflect on lessons learned and paths forward as we prepare for the 3rd Annual US Celebration of WHPCD that will take place October 3–4, 2022.

This year's conference attracted more than 278 registrants from at least 14 countries, including Australia, Bolivia, Canada, Ghana, Kenya, India, Oman, Lebanon, Mozambique, Philippines, South Africa, Spain, Switzerland, and 21 states across the US. The conference course directors and planning committee were comprised of an interdisciplinary team



Fig. 1. World Hospice and Palliative Care Day theme. Source: Worldwide Hospice Palliative Care Alliance (2021b). Campaign toolkit: Leave No One Behind. Available at: <http://www.thewhpc.org/resources-2021/category/campaign-toolkit-leave-no-one-behind>. *Reprinted with permission from the Worldwide Hospice Palliative Care Alliance.

representing nursing (WER, SP), medicine (ASE), spiritual care (LJA), clinical psychology (AJA), social work and bioethics (LB), and pharmacy (LAK). The event served as an invitation for a “global debriefing” about the realities of delivering hospice and palliative care services amid the COVID-19 pandemic and a critical international discourse regarding social injustice and health inequities. Moreover, the MSK conference leveraged the contributions of international experts in research and academia, policy and advocacy, clinical practice, organizational leadership, education and professional development, and faith communities to celebrate, support, and honor the endeavors of hospice and palliative care workers worldwide. Inclusion of patient and family caregiver participants, as well as a virtual Schwartz Rounds, highlighted the power of the human experience for both care recipients and health professionals.

2021 World Hospice and Palliative Care Day theme

Every year since 2005 the global palliative care community has chosen a theme for WHPCD that reflects an important and relevant aspect of palliative care. Previous themes have attempted to debunk palliative care myths or highlight germane facets of care, including the specific needs of seriously ill populations or a burgeoning area of palliative care. In 2021, the theme of *Leaving No One Behind: Equity in Access to Palliative Care*, featured groups that have historically experienced inequitable access to care and also poignant examples of overcoming inequity. Ten groups were identified that have lacked equitable access to palliative care (Table 1). The 2021 WHPCD campaign toolkit provides background information about the theme, ways that all members of society can contribute to increased access to palliative care, and the topline key messages (WHPCA, 2021b; see Table 2).

There is a disproportionate burden of serious health-related suffering for the poorest people in the world who lack access to hospice and palliative care services and the controlled essential medicines required for effective pain and symptom management (Knaul et al., 2018). Nearly 80% of the need for palliative care is for people living in low- or middle-income countries (LMICs) (Connor, 2020) and yet only 31% of currently available palliative

Table 1. Historically excluded groups with neglected access to palliative care

1. Those in low- and middle-income countries (LMICs)
2. People living in humanitarian crisis situations
3. Those that are incarcerated
4. People experiencing homelessness
5. Those who have contracted COVID-19
6. LGBTQ+ people
7. Frail older people
8. Those living with a physical or mental impairment
9. Those living with HIV and/or TB
10. Children and young people

Source: Worldwide Hospice Palliative Care Alliance (2021b). Campaign Toolkit: Leave No One Behind. Available at: <http://www.thewhpc.org/resources-2021/category/campaign-toolkit-leave-no-one-behind>.

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Table 2. Topline key messages of the 2021 World Hospice and Palliative Care Day

- 88% of the worldwide need for palliative care is not being met, meaning that millions of children and adults are being left behind — equity in access is a human right.
- Across the world, children and adults with palliative care needs are suffering and in pain because there is not equitable access to care. We must work together on World Hospice and Palliative Care Day to eliminate the barriers that maintain the *status quo*.
- Palliative care is essential to relieve pain and suffering, physical, psychological, social, and spiritual, related to COVID-19 — no one must be left behind.
- Health workers must be trained, supported, equipped, and financed to ensure equity in access to palliative care for all children and adults across the globe.
- To ensure equitable access to all children and adults who need it, palliative care must be mainstreamed into a country's healthcare system, including through Universal Health Coverage reforms.

Source: Worldwide Hospice Palliative Care Alliance (2021b). Campaign Toolkit: Leave No One Behind. Available at: <http://www.thewhpc.org/resources-2021/category/campaign-toolkit-leave-no-one-behind>.

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care delivery is in LMICs (Connor et al., 2021). This global palliative care and pain divide is the clear result of health inequities (WHPCA, 2021c). Efforts are underway to try to redress this

Table 3. 2nd Annual US Celebration of World Hospice and Palliative Care Day conference schedule and session topics

Session Title	Topics Addressed
International Models of Excellence in Palliative care	<ul style="list-style-type: none"> International palliative nursing education efforts through the End-of-Life Nursing Education Consortium (ELNEC); barriers and facilitators to international palliative care education; social and cultural considerations to expand access to palliative care education
Invited Rapid Fire Talks: Diversity, Inclusion, and Social Justice	<ul style="list-style-type: none"> “Disparities in Oncologist-Patient Communication,” “Promoting Effective and Equitable Communication and Care with LGBTQ+ Home Hospice Patients and Caregivers: Considerations for Practice, Education, and Research,” “Disparity of Preference? Considering and Responding to Haps in our Palliative Care Evidence Base,” “Centering Patient Perspectives: A Palliative Approach to Critical Conversations with African-Americans in the Wake of COVID-19,” “Palliative Care for Health Equity.”
Global Palliative Care Organizational Roundtable	<ul style="list-style-type: none"> Priorities and recommendations from the International Association for Hospice & Palliative Care, World Hospice Palliative Care Alliance, International Children’s Palliative Care Network, and Palliative Care in Humanitarian Aid Situations and Emergencies
Patient–Clinician Conversation	<ul style="list-style-type: none"> Interview of a patient living with cancer by their oncologist/palliative care physician
National Advocacy Efforts: How National Organizations Are Collaborating for Impact	<ul style="list-style-type: none"> Mission and purpose of the National Coalition for Hospice and Palliative Care; palliative care quality measures; legislative and congressional outreach; community palliative care; regulatory opportunities and considerations to expand access to palliative care
Visiting Virtual Schwartz Rounds	<ul style="list-style-type: none"> Interdisciplinary discussion on topics relating to the care of seriously ill patients during the COVID-19 pandemic, effects on palliative care team members, and insights on the emotional and social aspects of patient care
A Global Hospice & Palliative Care Fellowship Collaborative: Harvard, Tulane, and the University of California San Francisco	<ul style="list-style-type: none"> Program overview, curriculum, international sites (Pallium India, Makerere Mulago Palliative Care Unit, Gallup Indian Medical Center), resiliency, mentorship, and the use of tele-palliative/tele-education to provide global palliative care fellowship programs
Patients’ Diverse Spiritual Care Needs: An Interfaith Chaplain Panel	<ul style="list-style-type: none"> Spiritual and existential care assessment, screening, and delivery at generalist and specialist levels; palliative care spiritual education; use of art in legacy projects and spiritual care
Invited Rapid Fire Talks: Considerations Across the Spectrum of Hospice and Palliative Care	<ul style="list-style-type: none"> “Building a Framework for Existential Care: The Intersection of Palliative Care and Psychedelic Research;” “Resilience in the Aftermath of COVID;” “At the Crossroads of Bioethics, Cancer and Palliative Care;” “SGM Sensitivity Communication Skills Training for Oncology Care Providers: A Brief Overview”
Caregiver–Clinician Conversation	<ul style="list-style-type: none"> Exploration of a caregiver’s experience with a spouse’s terminal illness, role of early palliative care, importance of psychosocial support, and experience with home hospice at the end of life
Around the World — Global Hospice and Palliative Care	<ul style="list-style-type: none"> Palliative care priorities in developed and developing countries; analgesics and pain disparities; medical aid in dying; exemplars from South Africa and Uganda; recommendations from the Lancet Commission Report on Global Access to Palliative Care and Pain Relief

imbalance through the creation of community-based models of palliative care to fit different cultural contexts (Elk et al., 2020; Watts et al., 2020), evidence-based advocacy initiatives (Rosa et al., 2021d), and strategies to optimize the impact of the workforce to increase palliative generalist and specialist access (Rosa et al., 2021a, 2021c), as well as the dissemination of actionable indicators that will improve assessment of palliative care development globally (World Health Organization, 2021).

An international network, PallCHASE (Palliative care in Humanitarian Aid Situations and Emergencies), was recently formed with the purpose of working in partnership through a visible and effective network to advocate for palliative care integration in humanitarian crises or emergencies (PallCHASE, 2021). There are now millions of displaced persons due to war, climate change, disasters, and other emergencies worldwide and this number is expected to continue to grow. Displaced persons are among the most vulnerable in society, and include young children, older persons, and those with physical or mental health challenges and chronic conditions who would benefit from comprehensive palliative care (WHPCA, 2021d, 2021e, 2021f).

Homelessness is not limited to those in humanitarian emergencies — it is a worldwide problem secondary to structural inequities and lack of access to health services, especially mental health care (WHPCA, 2021g). Incarcerated individuals also lack access to palliative care, though there are a few model prison programs that are beginning to address this issue (WHPCA, 2021h).

Early in the HIV/AIDS pandemic, there was much stigma and resistance by healthcare workers to deliver care, particularly to LGBTQ+ people, and this is now being repeated in many ways during the current COVID-19 pandemic (WHPCA, 2021i).

Palliative care is recognized as an integral part of the right to health and is accepted as an essential component of universal health coverage, per United Nations Sustainable Development Goal 3.8 (Achieve universal health coverage, including financial risk protection, access to quality essential healthcare services and access to safe, effective, quality and affordable essential medicines and vaccines for all) (UN, 2021). The continuum of universal health coverage runs from promotion, prevention, and treatment to rehabilitation and palliative care. Without each of these components, health care is not universally complete nor accessible in each country. The annual MSK Celebration of WHPCD is just one event around the world that regularly elevates the need for the full and equitable integration of palliative care throughout the lifespan and across the care continuum.

A virtual coming together of friends, colleagues, and palliative specialists

Similar to the inaugural celebration in 2020, the 2021 program was supported and sponsored by Judith Nelson, MD, JD, Chief of the MSK Supportive Care Service, and William Breitbart, MD, Chair of the MSK Department of Psychiatry and Behavioral

Sciences. The course agenda was carefully crafted with consideration of globally relevant topics in the field, areas of growing palliative care research, and ongoing social, ethical, and cultural dilemmas. The format remained virtual to increase access to international participants and to respect the ongoing precautions and concerns related to the COVID-19 pandemic.

The event was organized through the MSK Continuing Medical Education program to offer continuing medical education credit to physicians. The cost for registration ranged from \$25 to \$85, depending on discipline. Complimentary registration was made available for all MSK employees and for palliative care professionals residing in LMICs, as well as palliative care students and trainees currently enrolled in a university program or completing a clinical fellowship or residency.

The conference consisted of 11 interactive sessions addressing diverse hospice and palliative care topics delivered by 37 interprofessional experts in palliative care. Topics included diversity, equity, inclusion, and cultural humility; advocacy and leadership; research and education; spiritual and existential care; complex communication needs; and social bioethical considerations (Table 3). Interdisciplinary palliative care scientists and advocates gave a total of nine rapid-fire talks, which focused on disparities in serious illness care for historically excluded populations, resilience in the face of COVID-19, bioethics, and psychedelic research. All sessions were recorded, except for the Schwartz Center Rounds session, and made available to registrants after the end of the conference, in addition to copies of presentation slides prepared by the speakers.

The opening keynote session was delivered by Betty Ferrell, PhD, RN, FPCN, FAAN, in which she described the international expansion of End-of-Life Nursing Education Consortium (ELNEC) to over 100 countries and territories, training more than 1.4 million ELNEC prepared nurses and other healthcare workers around the world, and translation of its curriculum 12 languages. Conference attendees learned of barriers and facilitators to global expansion of such palliative care curriculum including cultural influences, utilization of resources, stakeholder involvement, limited/lack of access to professional development, and the role of government agencies and legislation. Dr. Ferrell shared case exemplars in Kenya, Japan, India, Austria, Romania, and the Philippines showcasing the use of collaborative global partnerships and community health workers to increase international access to palliative care and highlighted lessons learned including use of local media outlets, curriculum that is inclusive to all healthcare professionals, and the importance of patience, persistence, and hope.

Palliative care leaders joined sessions focused on global palliative care priorities and hospice and palliative care policy. During a global palliative care organizational roundtable, Stephen Connor, PhD (WHPCA), Julia Downing, PhD, RGN (International Children's Palliative Care Network), Joan Marston, RN, MA (PallCHASE), and Katherine Pettus, PhD (International Association for Hospice and Palliative Care) discussed palliative care inequities and the actions each group was taking through improved professional and public education, advocacy, and research. Amy Melnick, MPA (National Coalition for Hospice and Palliative Care) gave an overview of policy action items in the US and provided guidance for palliative specialists to become engaged in the policy and advocacy process.

The 2021 program featured two deeply personal sessions showcasing the lived experiences of an oncology patient currently receiving palliative care and a bereaved caregiver who had been

the recipient of supportive palliative services throughout the illness trajectory of his husband. These personal narratives provided invaluable insight on the full impact of serious health-related suffering, the benefits of hospice and palliative care for both patients and families, and professional opportunities for enhancing palliative care delivery.

The patient session featured a courageous woman and her medical oncologist, Andrew Epstein, MD, as they discussed her journey with incurable colorectal cancer. The patient expressed how she chose to balance awareness of her incurable illness and a desire to understand how long people usually live in similar situations with the need to maintain faith in God that she would have a miraculously good outcome, all the while living each day as fully as possible. The patient spoke eloquently about how she decided to not dwell on her uncertain future, including how and when she would die. She expressed gratitude for her faith and family, as well as the care she had received to date, and trust in her oncology team. As a self-identified Black woman, she addressed racism in the health system and generously "called in" the audience for a sometimes difficult conversation. Audience members engaged her and her oncologist in questions about how she was able to cope and achieve this balance in both hope with optimism and awareness with living in the moment. One audience member commented that the patient's situation reminded her of the 1922 Langston Hughes poem "Mother to Son," particularly the words: "Life for me ain't been no crystal stair ... But all the time I've been a-climbin' on."

The following day, Allison Applebaum, PhD, associate attending behavioral scientist at MSK's Department of Psychiatry and Behavioral Sciences, interviewed her patient, who described his role as a caregiver to his husband who suffered from glioblastoma. The caregiver readily shared his experience from his husband's diagnosis, illness trajectory — including undergoing brain surgery and disease-targeted treatments, and the eventual functional losses, transition to hospice care, dying, death, and bereavement. He thoughtfully outlined challenges of the caregiver role including the physical aspects of care (e.g., lifting, bathing, toileting), coordinating care, maintaining hope, and preparing for death. This caregiver identified access to a robust interdisciplinary team, early palliative care, participation in formal and informal psychosocial support (e.g., Meaning-Centered Psychotherapy, support groups, bereavement counseling) as resources that allowed for adaptive coping and open communication with his spouse and care team. Their experience as a same-sex married couple experiencing a terminal illness, the role of health literacy, the impact of the COVID-19 pandemic, benefits of home hospice services, and opportunities for improvement were discussed.

On day two of the conference, an interdisciplinary palliative care team from the University of Colorado Hospital provided rare insight into their personal and professional experiences during COVID-19. Using photographs, song, poetry, and narratives, the team — an advanced practice nurse, music therapist, physician, and social worker — shared the barriers and facilitators of ensuring dignified care throughout the pandemic. Their individual stories of trauma, cumulative loss, racism, and unkindness demonstrated authenticity and courage, as well as the power of interprofessional and interdisciplinary collaboration, inspiring the audience to acknowledge the difficulties imposed by COVID-19 on the quality of care delivery and to use positive team relationships to support their work.

Conference participants were then offered the opportunity to choose from two break-out sessions: one on spiritual care needs

and the other on global fellowship programs. An interfaith chaplain panel representing spiritual care specialists from Buddhist, Christian, Jewish, and Muslim faiths offered experiences and approaches to caring for patients with diverse spiritual care needs. Physician colleagues from Harvard University, Tulane University, and University of California San Francisco shared a program overview and outcomes of their collaborative global hospice and palliative care fellowship in various sites in India and Africa.

Lukas Radbruch, MD, Chair of Palliative Medicine at the University of Bonn and Board Chair of the International Association for Hospice and Palliative Care, delivered the closing keynote presentation on disparities in access to palliative care across the world. Dr. Radbruch reviewed exemplars from locations such as Thiruvananthapuram, India and Soweto, South Africa where palliative care services are available but struggle with privacy issues (e.g., no walls within the clinical unit), limited access to clean water, and insufficient opioid supply. He explained how palliative care differs in resource-limited countries, where basic physiological needs (water, shelter, food, income) are a priority and volunteers are essential to delivering the care; compared to resource-rich countries where autonomy, dignity, sense of coherence is valued, and care is delivered by specialty-trained palliative care providers. Dr. Radbruch emphasized access to medically indicated opioids as a human rights issue to alleviate serious health-related suffering and recommended a balanced approach to opioid policy in alignment with international recommendations and global partnerships to improve the delivery of global palliative care.

Onward

The post-conference evaluations generated 115 responses from a total of 181 invitations sent by email. The higher response rate (64%) compared to the year prior was most likely related to the availability of continuing medical education credits and administrative support from the MSK CME program. Disciplines represented included nurses, nurse practitioners, social workers, physicians, physician assistants, chaplains, pharmacists, physical therapists, integrative medicine practitioners, students, and administrative and research personnel working in various clinical and academic settings including 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. Most (86%) identified as a clinician who manages or cares for patients, with 19% managing at least 20 patients weekly. Most participants rated the overall format of the program (70%) and length of the program (64%) as excellent. Almost all (98%) responded they would attend this meeting again virtually and 74% rated the overall virtual experience as excellent. All participants responded they were likely to recommend this course to a colleague.

Participants committed to change in areas of patient and inter-professional communication, patient education, teamwork roles and responsibilities, treatment, quality improvement, diagnosis and screening, safety, and other categories. Some specific examples from comments included: “I will help to continue to educate patients and their families prior to the end of life, because palliative care should be a continuum,” “Hold debriefings after deaths on the floor,” “Continue to work with my colleagues creating DEI [diversity, inclusion, and equity] content that will help people disrupt microaggressions,” and “Implement a QI [quality improvement] project on goals of care for our non-palliative care providers.” Almost all (99%) respondents reported the content was relevant

to practice with comments ranging from “Extraordinary sharing of current, real-world care and advocacy,” “Precise and practical examples,” “A lot was learned from attending this seminar,” “Gave me a better understanding of palliative care across the world,” and “Hearing about volunteers who help provide treatment to those in need restores my faith in humanity.”

Conclusion

The 3rd Annual US Celebration of WHPCD will be a two-day virtual event held on October 3–4, 2022. Next year, we will provide access to continuing nursing education credits in addition to physician continuing education credits. We will incorporate constructive feedback received from the evaluations and provide post-conference supplemental palliative care resources for participants to further sustain the information presented in the conference. Given its success, we will continue to use a live virtual platform over two days, alternating morning and evening times to allow for an international audience and accommodate for the uncertainties of the COVID-19 pandemic. Interdisciplinary representation and diverse perspectives will be maintained on the planning committee. The course directors will continue to identify and recruit leaders in hospice and palliative care as speakers and presenters in addition to marketing the program to local and international palliative care communities.

Importantly, the planning team will remain committed to equitable access to palliative care education by continuing to offer access to complimentary registration for colleagues living in low- and middle-income countries, students, and trainees. With these revisions and enhancements, along with early promotion of the event and use social media platforms, we expect heightened enthusiasm and participation for the 2022 event. As hospice and palliative care teams worldwide continue to adapt and adjust to patient and family needs, we hope our event will provide evidence-based support, inspiration, and a space for community building and wisdom sharing long into the future.

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- Worldwide Hospice Palliative Care Alliance (WHPCA)** (2021g) World day: Those people experiencing homelessness. Available at: <http://www.thewhpc.org/those-people-experiencing-homelessness>
- Worldwide Hospice Palliative Care Alliance (WHPCA)** (2021h) World day: Incarcerated people including prisoners. Available at: <http://www.thewhpc.org/prisoners>
- Worldwide Hospice Palliative Care Alliance (WHPCA)** (2021i) World day: LGBTQ+ people. Available at: <http://www.thewhpc.org/lgbtq-people>