



WHO Civil Society Roundtable

Palliative care integration in COVID-19 response and other WHO Strategic Priorities leading to comprehensive primary health care under universal health coverage

November 25, 2020

International Association for Hospice and Palliative Care
International Federation on Ageing
Worldwide Hospice Palliative Care Alliance





Table of Contents

Item	Page
Introduction	2
Objectives	2
Normative and technical framework	2
Speakers bios	4
Agenda	6
Speakers topics	7
Asks to WHO	8
Suggested next steps	8



WHO Civil Society Roundtable

Palliative care integration in COVID-19 response and other WHO Strategic Priorities leading to comprehensive primary health care under universal health coverage.

Introduction

The Global Atlas of Palliative Care, 2nd Edition (WHPCA, Oct.2020) estimates that nearly 57 million people annually, almost 70% of whom are older persons, need palliative care for the relief of severe health related suffering. Yet only about 7 million are receiving palliative care, leaving 50 million or more without this essential service. Notwithstanding the fact that member states adopted [WHA Resolution 67/19](#) (Strengthening of palliative care as a component of comprehensive care throughout the life course) in 2014, and approved the Declaration of Astana in 2018, the majority of WHO member states' lack the incentives and technical tools to successfully integrate palliative care into primary health care systems. COVID19 has revealed palliative care workforce, deficits in the face of the 2020 global tsunami of suffering and exacerbated longstanding supply chain issues blocking access to essential palliative care medicines on the WHO Model List. High level political leadership is needed to inspire WHO member states to integrate palliative care into the spectrum of essential services per the current global normative framework.

Objectives of Roundtable:

1. To raise the WHO Director General's, WHO Secretariat senior staff, and civil society organizations' awareness of the benefits palliative care integration in health systems and in particular in primary health care per several multilateral commitments;
2. To stimulate prioritization of palliative care integration in national COVID19 response and preparedness planning as well as in other disease control programmes;
3. To strengthen the palliative care narrative in WHO documents, guidance documents, resolutions and norms to ensure that patients and families in need have access to appropriate care throughout the life course;
4. To highlight the role that non-state actors in official relations with WHO can play in assisting the Secretariat at global, regional and country level, in partnership with member states, to remedy these workforce, access, and essential medicine deficits, to build back better, and to initiate strategies to prepare for future health emergencies.

Normative and Technical Framework

- a. Operational Paragraphs of WHA Palliative Care Resolution 67/19;
- b. Operational Paragraph 7/7 in [WHA73/1](#) directs WHO member states "to provide access to safe testing, treatment, and palliative care for COVID-19, paying particular attention to the protection of those with pre-existing health conditions, older people, and other people at risk, in particular health professionals, health workers and other relevant frontline workers;"



- c. The [WHO Temporary Guidance on Clinical Management of COVID-19](#) (May 2020) contains a palliative care module that includes Appendix 3 -- the Essential Package of Palliative Care -- a tool for member states detailing essential interventions, medicines, equipment, human resources and social supports;
- d. The [Joint Declaration on Access to Medicines](#) calls on governments to ensure that the procurement and supply of controlled medicines in countries meets the needs of patients, both those who have COVID-19 and those who require essential palliative care medicines for other medical conditions;
- e. The UN Decade of Healthy Ageing strategy <https://www.who.int/initiatives/decade-of-healthy-ageing>;
- f. WHO framework for national health policies, strategies, and plans: Engaging stakeholders <https://www.who.int/initiatives/decade-of-healthy-ageing> and https://www.who.int/docs/default-source/decade-of-healthy-ageing/final-decade-proposal/decade-proposal-final-apr2020-en.pdf?sfvrsn=b4b75ebc_5;
- g. International Year of Health and Care Workers 2021 <https://www.who.int/news/item/11-11-2020-2021-designated-as-the-international-year-of-health-and-care-workers>.



Speakers' Bios (in order of appearance)

Professor Lukas Radbruch - lukas.radbruch@ukb.uni-bonn.de

Professor Radbruch is the Chair of the Board of Directors of the International Association for Hospice and Palliative Care (IAHPC). The IAHPC is a membership-based organization in official relations with the WHO and dedicated to the development and advancement of hospice and palliative care to assure that any patient's and family caregiver's suffering is relieved to the greatest extent possible. Professor Radbruch has held the Chair of Palliative Medicine at the University of Bonn since 2010. He is the Director of the Department of Palliative Medicine, University Hospital Bonn, and Director of the Palliative Care Centre, Malteser Hospital Bonn/Rhein-Sieg. Before this he was the founding Director of the Department of Palliative Medicine at University Hospital, in Aachen. He has been President of the German Association for Palliative Medicine since 2014.

Ms. Rose Kiwanuka - rokiwanu@yahoo.com

Ms. Kiwanuka is the founder and former Executive Director of the Palliative Care Association of Uganda. She trained as a palliative care nurse in Oxford, Sunderland and the Netherlands because there were no palliative care programs in Uganda when she was a student. She was the first Registered Palliative Care Nurse in Uganda. Ms. Kiwanuka is a cancer survivor and, though retired, continues to advance palliative care in Uganda through her advocacy efforts.

Dr. Felicia Knaul - fknaul@gmail.com

Doctor Knaul is Director of the Institute for Advanced Study of the Americas and the Office of Hemispheric and Global Affairs and Professor at the Miller School of Medicine at the University of Miami. A health and social sector economist who has worked extensively in Latin America and the Caribbean, Knaul maintains a strong program of research and advocacy in the region, especially in Mexico, where she is Senior Economist at the Mexican Health Foundation. She is also the Founding President of Tómatelo a Pecho, a Mexican NGO that undertakes and promotes research, advocacy, awareness, and early detection of priority issues for the health of women. Her research focuses on global health, health financing, health systems and reform, cancer and especially breast cancer in low-and middle-income countries, access to pain control and palliative care, poverty and inequity, and gender equity. She currently chairs the Lancet Commission on Gender-based Violence and Maltreatment of Young People. From 2014-2017, Knaul served as Chair of the Lancet Commission on Global Access to Palliative Care and Pain Relief and lead authored its October 2017 report. She joined the IAHPC board in March 2020. Working with IAHPC leadership, Knaul works to implement, at the global, regional, and national levels, the research agenda and policy recommendations of the Lancet Commission report. She received her B.A. in international development from the University of Toronto and M.A. and Ph.D. in economics from Harvard University.

Professor Julia Downing - julia.downing@icpcn.org

Professor Downing is the Executive Director of the International Children's Palliative Care Network (ICPCN). She earned her nursing degree from the University of Wales College of Medicine in 1991 followed by a Diploma in Cancer Nursing (1994), a Masters in Medical Science in Clinical Oncology (1997), a Professional Certificate in Teaching and Learning in Higher Education (2000) and her PhD in 2006, completing the first PhD level studies on palliative care in sub-Saharan Africa. She is an experienced palliative care nurse, educationalist, researcher, and advocate who has been working in palliative care for 29 years, with 18 of those pioneering work internationally in Uganda, Africa, Eastern Europe and globally, developing palliative care services for adults and children. Before her executive director role, she held the position of Director of Education and Research for the ICPCN.



Dr. Ednin Hamzah - ednin@hospismalaysia.org

Dr. Hamzah is the Chief Executive Officer of Hospis Malaysia, a position held from 1997, where he leads the largest community palliative care service in the country. Dr. Hamzah teaches palliative care in several universities at both undergraduate and postgraduate levels. Nationally he has been involved in palliative care, cancer control and pain management and has been on the Boards of several National Organisations. He is active in international palliative care education and advocacy and is the current Vice Chairman of the Asia Pacific Hospice Palliative Care Network and a member of the Board of Trustees for the Worldwide Hospice Palliative Care Alliance.

Dr. Dingle Spence - dinglespence@gmail.com

Dr. Spence is founder and Chair of the Caribbean Palliative Care Association (CARIPALCA) based in Kingston, Jamaica. She trained in Clinical Oncology and Palliative Medicine. Dr. Spence is the Senior Medical Officer of the Hope Institute Hospital, Jamaica's only dedicated oncology and palliative care unit. She is also an Associate Lecturer in the Department of Medicine at the University Hospital of the West Indies in Kingston, Jamaica, and is currently the Acting Head of the Department of Radiotherapy at the Kingston Public Hospital. In 2005 she instigated and continues to teach an introductory course in palliative medicine for medical students at the University.

Mrs. Harmala Gupta - harmalagupta@hotmail.com

Mrs. Gupta is a cancer survivor, pioneer, and activist. After recovery, she felt it was her mission to create compassionate and caring support services for people with cancer and their families in India. In 1991, she founded the first peer-based cancer support group in India, 'Cancer Sahyog' in New Delhi. In 1996, realizing that the majority of people living with cancer needed continuing care, she founded 'CanSupport', which operates in New Delhi and the National Capital Region, providing free care to 3000 people living with cancer and their families. More recently, home care teams have been set up in Amritsar, in the state of Punjab, and more are on the anvil. CanSupport also runs out-patient services, day cares and a telephone helpline. Besides being President of CanSupport, Ms. Gupta is also founder and President of Cancer Care India, an umbrella organization of cancer support groups set up to advocate for the rights of people affected by cancer and to raise awareness about cancer in India.

Dr. Stephen Connor - sconnor@thewhpc.org

Dr. Connor is the Executive Director of the Worldwide Hospice Palliative Care Alliance (WHPCA), an alliance of 350 national and regional hospice and palliative care organizations in 105 countries. Dr. Connor has worked continuously in the hospice/palliative care movement since 1975 including as vice-president of the National Hospice and Palliative Care Organization (USA). He is now focusing on palliative care development internationally with the WHPCA and has worked on palliative care globally in over 25 countries. In addition to being a hospice and association executive, he is a researcher, educator, advocate, and psychotherapist, licensed as a clinical psychologist. Dr Connor has published over 145 peer reviewed journal articles, reviews, & book chapters on issues related to palliative care for patients and their families and is the author/editor of six books on palliative care including of new Global Atlas of Palliative Care (2020), in partnership with the WHO.

Agenda

Moderator: Professor Lukas Radbruch

TIME	SCHEDULE OF EVENTS	REPRESENTATIVE
15:00 – 15:05	Welcome Opening Remarks	Tedros Adhanom Ghebreyesus WHO staff
Panel 1 – Access to medicines		
15:05 - 15:10	<i>Introduction of speakers – panel 1</i>	Lukas Radbruch IAHPC
15:10 – 15:15	<i>Access to opioids and normative guidance from WHO</i>	Lukas Radbruch IAHPC
15:15 – 15: 20	<i>Strategies to advance access to medicines in low resource settings</i>	Rose Kiwanuka PCAU - Uganda
15:20 – 15: 30	<i>Strategies to ensure access to essential medicines for pain relief and palliative care</i>	Felicia Knaul FUNSALUD and Tomatelo a Pecho - Mexico
15:30 – 15:40	<i>Response and comments</i>	WHO Secretariat
Panel 2 – Underserved populations		
15:40 -15:45	<i>Introduction of speakers – panel 2</i>	Lukas Radbruch IAHPC
15:45 – 15:50	<i>Palliative care needs of children</i>	Julia Downing ICPCN
15:50 – 15:55	<i>Palliative care needs of older persons</i>	Ednin Hamzah Hospis Malaysia
15:55 – 16:00	<i>Palliative care and non-communicable diseases</i>	Dingle Spence CARIPALCA
16: 05 – 16:10	<i>Palliative care in the community</i>	Harmala Gupta CanSupport – India
16:10 – 16: 15	<i>Involvement of people with palliative care needs through civil society in the formal processes of WHO</i>	Stephen Connor WHPCA
16:15 - 16:25	<i>Response and Comments</i>	WHO Secretariat
16:30	<i>End of session</i>	



Speakers' Topics

1. Panel 1 – Access to Essential Palliative Care Medicines on WHO Model List

Health systems require adequate supplies of internationally controlled essential medicines (ICEMs) to manage the pain and symptoms of patients, many of whom will need palliative care. The May 2018 withdrawal of “Ensuring balance in national policies on controlled substances: Guidance for availability and accessibility of controlled medicines (2011),” left a normative and technical vacuum for member states that has yet to be filled. Meanwhile, patients around the world continue to experience severe health related suffering, which has only escalated during the pandemic. Endemic shortages in LMICs have been exacerbated by pandemic driven demand spikes and supply chain disruptions, resulting in unaffordable prices and stockouts. The Report of the Lancet Commission on Pain and Palliative Care showcases an essential package of palliative care medicines, basic equipment, and human resources that could alleviate much of avoidable health related suffering in LMICs.

2. Panel 2 – Underserved Populations

Most member states, including well-resourced countries, have yet to integrate palliative care into their COVID19 response and preparedness plans. Existing strategies are focused on virus spread mitigation and disease management while the palliative care needs of medically vulnerable populations are not considered. This reflects lack of understanding about palliative care’s critical role in strengthening health systems and alleviating the serious health-related suffering (SHS) associated with many health conditions including COVID19. Evidence shows that upstream public investments in workforce training, pharmaceutical supply chains, and health system strengthening can reduce downstream costs for households and public systems while relieving serious health related suffering of populations and improving health equity across the life course.

- 1. Children.** According to the updated Global Atlas, almost 4 million children needed palliative care in 2017. The majority are in the African and the South East Asian Regions (51.8% and 19.5% respectively), followed by the Eastern Mediterranean (12%), Western Pacific regions (7.7%), and the Americas (6.2%). In contrast the European region has only 2.8% of the total.
- 2. Older Persons.** According to the updated Global Atlas of Palliative Care, pre-pandemic estimates showed 40% of persons in need of palliative care aged 70 years or older and 27% aged 50-69. The pandemic has dramatically increased the number of older persons in need of palliative care and illuminated tragic deficits in long term care in HIC countries.
- 3. Patients and families with NCDs.** Providing palliative care (PC) for patients with NCDs in LMIC settings is difficult even under normal circumstances. Recognition of the need for palliative care in humanitarian crises such as the pandemic is lacking. COVID19 is delaying access to essential NCD care for patients with palliative care needs. WHO surveys show significant disruption of NCD prevention, treatment, and palliative care due to blocked supply chains and workforce shortages.
- 4. Patients in the Community.** Palliative care aims to prevent and relieve serious health-related pain and suffering - physical, emotional, social, spiritual, practical - associated with chronic or life-threatening illnesses of all patients and families. Communities worldwide facing care needs that exceed the capacities of most formal health systems benefit from the services of community health workers. Patients sent home by formal health systems and told that “nothing more can be done,”



need appropriately trained community members who can provide palliative care that accompanies households through challenging times.

- 5. Persons with palliative care needs (PWPCNs).** Adults and children with PC needs, especially in LMICs, face multiple difficulties accessing essential services. Structural barriers services, treatments, medications has exacerbated their medical vulnerability during the COVID19 pandemic and diminished their ability manage life-threatening illness. Many patients fear that their lives are seen as not 'worth saving'. PWPCDs should be involved in all aspects of governance, policy making, advocacy, and education

Asks to WHO

Panel 1

Professor Lukas Radbruch - Access to opioids and normative guidance from WHO

We ask the WHO to:

1. Finalize the revision and publication of the *Ensuring Balance in National Policies on Controlled Substances* and *Guidelines on the Pharmacological Treatment of Persisting Pain in Children with Medical Illnesses* as soon as possible.
2. Continue strengthening the existing relationship with the INCB and the UNODC leading to stronger messaging and more comprehensive strategies for technical support to countries.
3. Provide member states with the technical assistance with the foundational work that leads to the rational use of opioids for legitimate medical needs.

Dr. Felicia Knaul - Strategies to ensure access to essential medicines for pain relief and palliative care

1. Can WHO, in partnership with Non state actors, produce a detailed analysis to assess the supply and demand factors that characterise the market for pain relief medicines, especially morphine, to explain the exceptionally large variation in prices? This information should help to develop the price-stabilisation platforms recommended by the Lancet Commission and enable countries to have access to better international pricing data as a tool for effective negotiation by countries and for civil society advocacy.
2. Can WHO facilitate the establishment of global or regional purchasing and procurement strategic funds to facilitate access to the medicines outlined in the Essential Package, especially immediate-release oral morphine, to secure best quality and price, and to provide technical assistance to countries in establishing safe and effective supply chains?

Ms. Rose Kiwanuka - Strategies to advance access to medicines in low resource settings

Director General: In many countries, private and external sources fund palliative care training and service delivery. This is unsustainable given population aging and the increasing burden of NCDs.

How can the Secretariat better operationalise:

1. WHA67/19's directive in OP 2(5) "to explore ways to increase the availability and accessibility of medicines used in palliative care through consultation with Member States and relevant networks and civil society, as well as other international stakeholders, as appropriate"?
2. WHA67/19's directive in OP 2(10) "to work with Member States to encourage adequate funding and improved cooperation for palliative care programmes and research initiatives, in particular in resource-poor countries"?

Panel 2

Professor Julia Downing - Palliative care needs of children

1. Strongly recommend governments to integrate children's palliative care throughout the health systems, in line with the WHA resolution.
2. Promote accessibility to the essential medicines for children required in palliative care, ensuring that they are available in paediatric doses and formulations throughout countries and in humanitarian settings.



3. Finalize, as soon as possible, the revised WHO guidelines for managing pain in children and for ensuring balanced national policies for access and safe use of controlled medicines.
4. Mobilize resources and work with WHO regional offices and Member States to encourage adequate funding for implementation of children's palliative care service provision and palliative care education of health workers.
5. Request member states to integrate children's palliative care into all maternal and child health programmes, including perinatal/neonatal care, midwifery, infectious and non-communicable diseases, to ensure palliative care is an integral component of all relevant global disease control and health system plans.

Dr. Ednin Hamzah - Palliative care needs of older persons

To support our government to improve the care of the people we care for, we respectfully request WHO:

1. To develop WHO guidelines to improve the policy framework for palliative care for older persons in addressing their special needs.
2. To ensure that palliative care for older persons is included in all relevant WHO reports and Healthy Ageing publications regarding health and social care through the life course.

Dr. Dingle Spence – Palliative care and non-communicable diseases

1. We request that WHO's messaging on NCD prevention and control always include palliative care to ensure that member states recognize, implement, and resource policies appropriately.
2. We request WHO assistance in collaboration with the Regional Office for the Americas - the Pan American Health Organization - to provide stronger messaging urging CARICOM governments to recognise palliative care as an essential component of healthcare services for patients with NCDs including cancer, with a strong focus on incorporation into existing primary care systems.
3. We request WHO to help develop a global accountability and monitoring mechanism that includes time-bound and measurable palliative care implementation and progress indicators.

Mrs. Harmala Gupta - Palliative care in the community

The WHO has designated 2021 the year of the health and care worker. We ask WHO to support us by:

1. Providing policy makers in India with the technical guidance and tools to train community health care workers. Their effectiveness depends on continuity of care that supports referral and transportation of patients to higher levels of the public health system as appropriate.
2. Require integration of palliative care, an essential component of primary health care, in all relevant Secretariat promotional material, reports and publications across WHO divisions, including sexual and reproductive health, maternal child and adolescent health, NCDs, HIV/AIDS, TB, Healthy Ageing, and Prison Health.



Dr. Stephen Connor - Involvement of people with palliative care needs through civil society in the formal processes of WHO

The voice of people living with palliative care needs, along with broader civil society, is crucial to build commitment and action by UN agencies and member states to ensure access to palliative care as an essential health service, including as part of Universal Health Coverage reforms. However, these voices are rarely enabled and supported to be heard by policy makers. Ensuring a strong civil society voice, including those with palliative care needs, in decision-making and information fora at the global, regional and national level is crucial to meeting our aims of access to palliative care for all those who need it and to ensure that palliative care is included in plans, budgets and monitoring frameworks at all levels. We request WHO to support greater interaction between civil society and its member states, where it has the power to do so, including for instance through:

1. Opening up WHO's member state briefing sessions to civil society
2. Supporting continued interaction between civil society and member states at the World Health Assembly and other high-level fora
3. Supporting a High-level Commission on Palliative Care which includes people with palliative care needs alongside WHO and member states.

Suggested Next Steps

We respectfully suggest the following next steps:

1. Form a Palliative Care Working Group that includes WHO Senior Staff and representatives of relevant civil society organizations and experts from the field, to plan integration of palliative care across all relevant WHO divisions.
2. Develop an associated High-Level Commission on Palliative Care and Long Term Care and a WHO Palliative and Long-Term Care Charter.

A first meeting of this Working Group could take place in January 2021 before the WHO EB meeting to review agenda and opportunities to introduce palliative care into the discussion.