

# Redefining palliative care – a new consensus-based definition

Lukas Radbruch, Liliana De Lima, Felicia Knaul, Zipporah Ali, Sushma Bhatnagar, Charmaine Blanchard, Eduardo Bruera, Rosa Buitrago, Claudia Burla, Mary Callaway, Esther Cege Munyoro, Carlos Centeno, Jim Cleary, Stephen Connor, Odontuya Davaasuren, Julia Downing, Kathy Foley, Gilles Forte, Cynthia Goh, Wendy Gomez-Garcia, Richard Harding, Quach T Khanh, Phillippe Larkin, Mhoira Leng, Emmanuel Luyirika, Joan Marston, Sebastien Moine, Hibah Osman, Katherine Pettus, Christina Puchalski, M.R. Rajagopal, Dingle Spence, Odette Spruijt, Chitra Venkateswaran, Bee Wee, Roberto Wenk, Roger Woodruff, Jinsun Yong and Tania Pastrana

## Online annex on methodology and results from the consensus process

The methodology of the Delphi consensus process as well as the main results from this process are reported in a paper submitted for publication in the Lancet. The following tables and boxes summarize additional information that may be useful for the understanding of the process and the resulting consensus definition.

**Table 1: Changes in the understanding of palliative care <sup>1</sup>**

	FROM	Change TO
Concepts	Terminal disease	Advanced progressive chronic disease and acute conditions that result in serious health related suffering.
	Death weeks or months	Limited life prognosis
	Cancer	All chronic progressive diseases and conditions
	Disease	Condition (multi-pathology, frailty, dependency, etc)
	Mortality	Prevalence
Model of care and organisation	Dichotomy curative - palliative	Synchronic, shared, combined care
	Specific OR palliative treatment	Specific and palliative care as needed
	Prognosis as criteria intervention	Complexity as criteria
	Late identification in specialist services	Early identification in community and all settings
	Rigid one-directional intervention	Flexible intervention
	Passive role of patients	Autonomy / Advance care planning
	Reactive to crisis	Preventive of crisis / Case management
	Fragmented care	Integrated care
Perspective for planning	Palliative care services	+ Palliative care everywhere
	Specialist services	+ Actions in all settings of health and social care
	Institutional approach	Institutional and Community approach
	Services' approach	Population approach
	Individual service	System approach

**Table 2 – Members of the Expert Group in phase 1 and phase 3 of the consensus process:**

<b>Name</b>	<b>Profession</b>	<b>Residence</b>
1. Bee Wee	Physician - Researcher. Head of Palliative Care Research and Development, Sir Michael Sobell House in Oxford	UK
2. Carlos Centeno	Physician and Researcher - Education in PC. ATLANTES Professor Palliative Care Universidad de Navarra	Spain
3. Charmaine Blanchard	Physician - Palliative Care. Senior Lecturer and Researcher, University of the Witwatersrand, Johannesburg	South Africa
4. Chitra Venkateswaran	Physician - Mental health and Palliative Care. Founder and Clinical Director MEHAC Foundation	India
5. Christina Puchalski	Physician - Spiritual care. Director, The George Washington University Institute for Spirituality and Health (GWish)	USA
6. Claudia Burla	Physician - Geriatrician, Secretary of the board, International Association of Gerontologists	Brazil
7. Cynthia Goh	Physician - chairperson of the Asia Pacific Hospice and Palliative Care Network (APHN)	Singapore
8. Dingle Spence	Physician - palliative care. Regional leader, president Caribbean Palliative Care Association (CARIPALCA)	Jamaica
9. Eduardo Bruera	Physician - Palliative care in cancer, Researcher, Palliative Care Chair MD Anderson Cancer Center	USA
10. Emmanuel Luyirika	Physician - Regional leader, Executive Director African Palliative Care Association (APCA)	Uganda
11. Esther Cege Munyoro	Physician - Palliative Care. Coordinator palliative care unit Kenyatta National Hospital, Nairobi,	Kenya
12. Hibah Osman	Physician - Palliative Care. Executive and Medical Director Balsam Center, Beirut	Lebanon
13. Jim Cleary	Physician – Palliative Care in cancer, Researcher, Director WHO Collaborating Center in Policy and Pain Studies Group (PPSG)	USA
14. Jinsun Yong	Nurse - Education in Palliative Care. Director WHO Collaborating Centre for Training in Hospice & Palliative Care	South Korea
15. Joan Marston	Nurse -Palliative Care in Humanitarian Aid Situations and Emergencies network (PALCHASE)	South Africa
16. John Beard	Physician- Healthy Ageing WHO	Switzerland
17. Julia Downing	Nurse - Professor Palliative Care Makerere - International Children's Palliative Care Network (ICPCN)	Uganda
18. Katherine Pettus	Political science - Advocacy International legal frameworks, access to medicines for palliative care. Advocacy Officer IAHP	USA
19. Kathy Foley	Physician - Palliative care specialist. Adviser to IAHP	USA
20. Liliana De Lima	Psychologist, HC administrator, Executive Director IAHP	USA / Colombia
21. Lukas Radbruch	Physician – Professor Palliative Care, University Bonn, Chair IAHP	Germany
22. M.R. Rajagopal	Physician - Palliative Care Advocate, Chair Pallium India	India
23. Mary Callaway	Administrator - Board member IAHP and APCA	USA
24. Mhoira Leng	Physician - Palliative care development, education. Lead for PC Makerere University, and Cairdeas International Palliative Care Trust	Uganda
25. Odette Spruitt	Physician - Palliative Care, Assoc professor Peter MacCallum Cancer Centre, Australasian Palliative Link International	Australia
26. Odontuya Davaasuren	Physician - Professor Palliative Care, Mongolian Palliative Care society	Mongolia
27. Phillippe Larkin	Nurse, researcher - President of European Association for Palliative Care (EAPC)	Ireland

28. Quach T Khanh	Physician - Ho Chi Minh City Hospital - Director palliative Care unit	Vietnam
29. Richard Harding	Researcher - Director of the Centre for Global Health Palliative Care Kings College, London	UK
30. Roberto Wenk	Physician - Palliative Care director - National Palliative Care program FEMEBA	Argentina
31. Roger Woodruff	Physician - Founder IAHPC - Retired professor Palliative Care	Australia
32. Rosa Buitrago	Pharmacist - Dean school of pharmacy - University of Panama	Panama
33. Sebastiane Moine	Physician - primary palliative care International Primary Palliative Care Network (IPPCN)	France
34. Stephen Connor	Psychologist, Administrator and Researcher, ED Worldwide Hospice Palliative Care Alliance (WHPCA)	USA
35. Sushma Bhatnagar	Physician - Professor Palliative Care, AIIMS Institute, New Delhi, India	India
36. Tania Pastrana	Physician and Researcher - Aachen University. President Latin American Association for Palliative Care	Germany/ Colombia
37. Wendy Gomez-Garcia	Pediatric oncology - Global Pediatric Medicine Collaborator for Haiti & Dominican Republic, St. Jude Children's Research Hospital	Dominican Republic
38. Zipporah Ali	Physician - Executive Director Kenya Hospices and Palliative Care Association (KEHPCA)	Uganda

**Table 3 – Components of the proposed palliative care definition and level of consensus in Phase 2 of the Delphi consensus process (419 IAHP members from countries of all income levels)**

	Item	% Level of consensus	Mean (SD)
1	Palliative care is the active, holistic care of patients with serious health-related suffering	90.0	4.5 (.821)
2	Palliative care aims to improve the quality of life of patients with severe illnesses	93.9	4.7 (.626)
3	Palliative care is provided to patients, their families and caregivers	98.5	4.8 (.397)
4	Palliative care includes early identification, comprehensive assessment and adequate management of: - Physical issues including pain and other distressing symptoms - Psychological distress - Spiritual distress - Social needs	99.5	4.9 (.339)
5	Whenever possible, these palliative care interventions must be evidence based	93.4	4.6 (.616)
6	Is applicable throughout the course of an illness, relative to the patient's needs	96.1	4.8 (.555)
7	Is provided in conjunction with disease modifying therapies whenever needed	96.9	4.8 (.525)
8	May positively influence the course of illness	93.4	4.6 (.660)
9	Provides support to help patients live as fully as possible until death by facilitating effective communication and helping patients and families determine goals of care.	99.0	4.9 (.355)
10	Intends neither to hasten nor postpone death, affirms life, and recognizes dying as a natural process	96.2	4.8 (.601)
11	Provides support to help the family and caregivers during the patients' illness and in their own bereavement	97.1	4.8 (.474)
12	Must be provided in accordance with the cultural values and beliefs of the patient and family	96.6	4.8 (.532)
13	Is applicable throughout all health care settings (from primary to tertiary) and can be provided by health care professionals with basic palliative care training	92.7	4.6 (.769)
14	Requires specialist palliative care with a multiprofessional team for complex cases	98.1	4.9 (.472)
<b>In order to achieve palliative care integration, governments must:</b>			
1	Adopt adequate policies and norms that include palliative care in health laws and national health programs	93.7	4.9 (.296)
2	Ensure access to essential medicines for pain relief and palliative care, including pediatric formulations	93.9	5.0 (.199)
3	Integrate palliative care services in a continuum of care with emphasis on community-based care	93.0	4.9 (.378)
4	Ensure access to adequate palliative care for vulnerable groups, including children and older persons	98.5	4.9 (.320)
5	Include palliative care as an integral component of the ongoing education and training offered to care providers, including basic, intermediate, and specialist training, as well as continuing education for health care workers and caregivers	93.9	4.9 (.251)

**Table 4 – Categories of additional comments submitted by participants in Phase 2 of the Delphi process (419 IAHPc members from countries of all income levels)**

<b>Category</b>	<b>Number of Comments</b>
Education	28
Palliative Care in the community	16
Access to essential medicines	12
Policy	11
Service Provision	8
Funding/Resources	6
Research	4

## Online Box 1 – Historical background of hospice and palliative care

While this paper focuses on the term palliative care, generating an encompassing framework and consensus-building process begins with an understanding of its origin. Other terms such as “hospice care”, “supportive care”, “care of the dying” and “terminal care” have been used interchangeably with “palliative care”.<sup>2</sup>

In 1967 Dame Cicely Saunders founded Saint Christopher’s Hospice, the first modern hospice. She is recognized for establishing the discipline and the culture of palliative care, developing intensity scales for pain evaluation, implementing effective pain management and for insisting that dying people needed dignity, compassion, and respect, as well as advocating for rigorous scientific methodology in the testing of treatments.<sup>3</sup> She introduced the idea of “total pain,” which included the physical, emotional, social, and spiritual dimensions of distress.<sup>4</sup> All of these components are now integral to palliative care.

The “palliative” term derives from Latin word *pallium* meaning to ‘mask’ or ‘cloak’ The idea was that palliative care could protect and cover those patients who are “left out in the cold” curative medicine could no longer treat them. Doctor Balfour Mount introduced the term ‘palliative care’ in 1973<sup>5</sup> when, after visiting St Christopher’s Hospice in London, he opened a new hospital ward for terminally ill patients at the Royal Victoria Hospital, in Montreal, Canada. Dr. Mount was hesitant of using the term “hospice” because in France the word had a negative connotation that suggested mediocrity of care.<sup>6</sup>

The terms “palliative care” and “hospice care” have been used to mean a variety of different things. Historically, “hospices” were places of temporary or permanent stay, including homes for the destitute, for orphans, for pilgrims, and for the dying who had no one else to care for them.<sup>7</sup> The word “hospice” derives from the Latin *hospes*, a word that includes host, guest or stranger.<sup>8</sup> In some countries such as the United Kingdom, “hospice” is a free-standing palliative care inpatient unit, while in Germany and the USA it tends to be a unit run by volunteers or home care programs for patients at the end of life. In France, a “hospice” still refers to a refuge for travelers needing food and shelter, and in Germany and Israel may even mean “hotel”.

**Online Box 2 - Health conditions that are incorporated into serious health-related suffering (SHS) based on Lancet Commission report <sup>9</sup> (sorted by prototypical illness trajectories, adapted from <sup>10</sup>) (n=20)**

**Illness trajectory 1 (Cancer):**

- malignant neoplasms (cancers)
- leukemia

**Illness trajectory 2 (Organ failure)**

- Artherosclerosis; cerebrovascular disease; chronic ischemic heart diseases;
- non-ischemic heart diseases
- lung diseases
- diseases of the liver
- renal failure

**Illness trajectory 3 (Frailty, Progressive neurological conditions):**

- HIV disease
- tuberculosis
- degeneration of the CNS; dementia
- inflammatory disease of the CNS
- musculoskeletal disorders
- protein energy malnutrition

**External causes**

- injury
- poisoning
- other external causes

**Various causes (certain infectious diseases, mental illnesses)**

- hemorrhagic fevers
- premature birth and birth trauma
- congenital malformations

Note: Specific health conditions resulting from diabetes that often generate a need for palliative care (cerebrovascular disease, renal failure, cardiomyopathy and heart failure, chronic ischemic heart disease, and atherosclerosis) are listed individually.

## References

1. Gomez-Batiste X, Connor S, editors. Building integrated palliative care programs and services. Barcelona: Liberdúplex; 2017.
2. Radbruch L, Payne S, Bercovitch M, et al. White paper on standards and norms for hospice and palliative care in Europe part 1- recommendations from the European Association for Palliative Care. *European Journal of Palliative Care* 2009; **16**: 278-89.
3. Clark D. Cicely Saunders - a life and legacy. New York: Oxford University Press; 2018.
4. Richmond C. Dame Cicely Saunders. *British Medical Journal* 2005; **331**: 238.
5. Billings JA. What is palliative care? *J Palliat Med* 1998; **1**(1): 73-81.
6. Philips D. McGill Portraits. Balfour Mount: The father of palliative care in Canada, physician Balfour Mount on the legacy of Cicely Saunders, the start of palliative care, and the true meaning of medical aid in dying. 2018.  
<https://www.mcgill.ca/palliativecare/portraits-0/balfour-mount> (accessed 25.4.2019).
7. Société d'histoire et d'archéologie de Beaune. Un visite à l'Hôtel-Dieu de Beaune In: Société d'histoire et d'archéologie de Beaune, ed. Histoire, lettres, sciences et arts - memoirs année 1912; 1912: 173-97.
8. Robbins J, Moscop J. Caring for the Dying Patient and the Family. 3rd ed. New York: Springer; 1995.
9. Knaul FM, Farmer PE, Krakauer EL, et al. Alleviating the access abyss in palliative care and pain relief-an imperative of universal health coverage: the Lancet Commission report. *Lancet* 2018; **391**(10128): 1391-454.
10. Lynn J, Adamson DM. Living well at the end of life: adapting health care to serious chronic illness in old age. Arlington, VA, : Rand Health; 2003.