

Original Article**Redefining Palliative Care—A New Consensus-Based Definition**

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Abstract

Context. The International Association for Hospice and Palliative Care developed a consensus-based definition of palliative care (PC) that focuses on the relief of serious health-related suffering, a concept put forward by the Lancet Commission Global Access to Palliative Care and Pain Relief.

Objective. The main objective of this article is to present the research behind the new definition.

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Methods. The three-phased consensus process involved health care workers from countries in all income levels. In Phase 1, 38 PC experts evaluated the components of the World Health Organization definition and suggested new/revised ones. In Phase 2, 412 International Association for Hospice and Palliative Care members in 88 countries expressed their level of agreement with the suggested components. In Phase 3, using results from Phase 2, the expert panel developed the definition.

Results. The consensus-based definition is as follows: Palliative care is the active holistic care of individuals across all ages with serious health-related suffering due to severe illness and especially of those near the end of life. It aims to improve the quality of life of patients, their families and their caregivers. The definition includes a number of bullet points with additional details as well as recommendations for governments to reduce barriers to PC.

Conclusion. Participants had significantly different perceptions and interpretations of PC. The greatest challenge faced by the core group was trying to find a middle ground between those who think that PC is the relief of all suffering and those who believe that PC describes the care of those with a very limited remaining life span. *J Pain Symptom Manage* 2020;60:754–764. © 2020 The Authors. Published by Elsevier Inc. on behalf of American Academy of Hospice and Palliative Medicine. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

Key Words

Definition of palliative care, consensus, Delphi method, quality of life, relief of suffering, low or middle income countries

Introduction

Access to palliative care (PC)—an essential component of health care and integral to Universal Health Coverage^{1,2}—is still grossly inadequate or nonexistent in most parts of the world.³ The Lancet Commission on Global Access to Palliative Care and Pain Relief (hereafter referred to as The Lancet Commission) estimated that annually, more than 61 million people experience health conditions associated with suffering that could be significantly ameliorated through PC. At least 80% lack access to even the most basic PC interventions, such as pain medication.⁴

Appropriately defining and delimiting the nature and scope of PC is key for integration into the care continuum, to identifying the human, financial and physical resources required to meet global need, and to close the enormous inequitable divides in access. Yet, as clinical science and capacity to deliver health care have evolved, the debates around the definition of PC have become more intense and complex.⁵

PC initially and historically focused on alleviating the relief of suffering at the end of life. However, it is now considered best practice⁶ and is increasingly implemented earlier in the trajectory of life-threatening health conditions. Furthermore, the historical development of PC was focused largely on patients with cancer, whereas it is now being integrated into treatment of all life-threatening health conditions. Existing research suggests that PC is both effective in reducing symptom burden and improving quality of life, cost effective, and synonymous with quality of care.^{7,8}

A consensus on the definition is required for conceptual clarity in PC, which in turn impacts on scope of practice, therapeutic aims, and outcome assessment. Lack of conceptual clarity may hamper the efforts of countries, especially those of low income and

middle income, to implement PC and thus to achieve universal health care.

The Lancet Commission identified the need to review and revise the definition of PC. As part of its agreement of work as a nongovernmental organization in official relations with the World Health Organization (WHO), the International Association for Hospice and Palliative Care (IAHPC) took on this task.

The objective of this article is to present the research behind the new definition. We developed a consensus-based definition of PC that focuses on the relief of serious health-related suffering (SHS), a concept put forward by the Lancet Commission, that is, timely and is applicable to all patients regardless of diagnosis, prognosis, geographic location, point of care, or socioeconomic level. This article describes the process undertaken by IAHPC, the findings of the consensus-building exercises, and presents the resulting definition and recommendations.

Definitions, Terminology, and Scope of PC

In 1990, WHO published a definition of PC,⁹ and in 1998, a specific one for children.¹⁰ The WHO definition was revised in 2002 (Table 1).¹¹ This definition expanded the scope of PC considerably and placed a much-needed focus on a public health approach. However, there has also been criticism of this definition. It limits PC to problems associated with life-threatening illnesses, rather than the burdensome experience of patients with severe and frequently multiple chronic conditions. The range and severity of potential PC needs may be more relevant indicators of need for these patients than prognosis alone.¹²

Some PC specialists have expressed doubts as to the meaning of impeccable as well as to whether this is a

Table 1
PC—Definition of the WHO¹¹

PC is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual.

PC:

- Provides relief from pain and other distressing symptoms;
- Affirms life and regards dying as a normal process;
- Intends neither to hasten or postpone death;
- Integrates the psychological and spiritual aspects of patient care;
- Offers a support system to help patients live as actively as possible until death;
- Offers a support system to help the family cope during the patient's illness and in their own bereavement;
- Uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated;
- Will enhance quality of life and may also positively influence the course of illness;
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications

PC = palliative care; WHO = World Health Organization.

valid marker for assessment and treatment. Other areas of the definition of PC that require clarification are that it can be provided wherever the patient's other care takes place, is needed for chronic and terminal illness, and can be adapted in different geopolitical, cultural, and economic settings.¹³ More recently, other changes in the concept of PC have been discussed, including different models of care provision and organization of care.^{5,14}

Some organizations, such as the African Palliative Care Association and the Asian Pacific Hospice Palliative Care Network, have adopted the WHO definition, whereas others have adopted their own definitions of PC.^{15–20} The International Children's Palliative Care Network has a dedicated section in its Web site that presents the various definitions used for children's PC.²¹

A review of the different definitions revealed variance in *how* (as a medical specialty or as a general approach) and *when* (end of life or early integration) PC is implemented within the care continuum.²² Integrating PC early in the course of illness may both improve symptom control and quality of life, and early integration into treatment protocols for both adults and children has been advocated.^{23,24} This is particularly important for diseases other than cancer, for example, HIV and multidrug-resistant tuberculosis in Sub-Saharan Africa,²⁵ where sufficient evidence exists to support provision of PC based on need rather than on prognosis or disease stage. PC is now also being considered an important component in responding to acute epidemics²⁶ and humanitarian emergencies.²⁷

Despite of these differences, there seems to be a common understanding and discourse. An analysis of 37 English and 26 German definitions identified the prevention and relief of suffering and improvement of quality of life as common shared goals of PC.²²

In 2017, the Lancet Commission presented a framework to measure the global burden of SHS as a metric of PC need.⁴ Suffering is defined as health related when it is associated with illness or injury of any kind. Health-related suffering is serious when it

cannot be relieved without professional intervention and when it compromises physical, social, spiritual, and/or emotional functioning. The estimation of SHS includes the 20 health conditions or illness groups that are most likely to generate a need for PC.^{4,14} This new approach resulted in an even broader conceptualization of the scope of PC. The Lancet Commission recommended that the WHO definition be reviewed and revised to better encompass all levels of the health care system and varying socioeconomic conditions, especially in low-income and middle-income countries (LMICs) where medical professionals often have the difficult task of caring for patients with severely limited access to necessary medicines, equipment, or training.

Methodology

A three-phased consensus process was designed in accordance with the Conducting and REporting DELphi Studies guideline for PC (Fig. 1).²⁸ Some additional information on the consensus process, for example, the names of the participants in Phases 1, 2, and 3, are available online.¹⁴

Phase 1

In March 2018, the IAHPCC formed a core group of PC experts and WHO representatives (Lukas Radbruch, Roberto Wenk, Gilles Forte, Marie-Charlotte Bousseau, and Liliana De Lima). Tania Pastrana served as research adviser. All materials such as survey questionnaires used in the three phases were piloted by the core group.

The core group identified 38 experts, who all agreed to participate in the expert group.¹⁴ The experts were regionally and professional diverse and located in countries in all income levels (Table 2). Board members of international PC organizations were included, as well as PC leaders specialized in pediatrics, geriatrics, research, spiritual care, primary

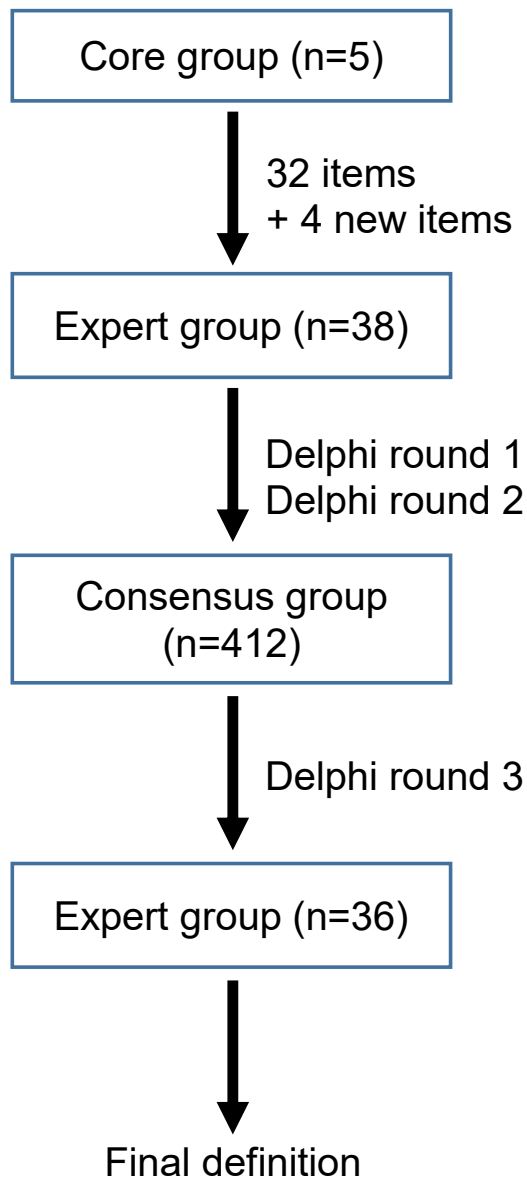


Fig. 1. Flowchart for consensus process.

care, pharmacy, and health economics. Given that one of the tasks of the members of this group was to revise and approve the project proposal and the proposed methodology, in this phase, we included only persons with strong clinical and research background.

The WHO definition of PC was broken down into its main components resulting in 32 items. Using an online survey tool (SurveyMonkey[®], Survey Monkey [Corp.], San Mateo, CA), these components were presented to members of the expert group in a first round of a Delphi consensus procedure. The survey also included four additional components considered by the core group to be absent from the WHO definition. For each component, participants were asked to select one of four options (stay as is; revise; delete; and

do not know/not sure) and were given the opportunity to edit and suggest language.

In a second Delphi round, participants were provided with anonymized results from the first round and were given the opportunity to change or modify their initial response. After the second round of Delphi, components receiving approval of 70% or more were left as they were. Other components were revised based on the suggestions of the participants.

Phase 2

Participants in this phase were recruited from among the 1025 members registered with the IAHPD as of April 2018. Excluding undergraduates, 1014 members were eligible for the survey. The IAHPD members were stratified by their respective countries' socioeconomic level according to the World Bank classification (high income, upper middle, lower middle, and low income).²⁹ From each country income-level group, 150 members were randomly selected. The selected members received an electronic mail invitation between June and July 2018 to participate in the survey. The IAHPD members who responded to the invitation received a link to an online survey.

Participants were assured of confidentiality and privacy. The respondents' data from the survey were stored in a SurveyMonkey password-protected account.

Participants were asked to rank their agreement with each component that was approved or revised in Phase 1 using a Likert scale (completely disagree, mostly disagree, neither agree nor disagree, mostly agree, completely agree, and do not know). They could also provide additional comments in free-text fields.

Consensus was defined a priori as $\geq 70\%$ of answers scoring 5 (strongly agree) or 4 (agree), and the mean score >4 on the Likert scale.

Phase 3

Based on the components reaching consensus in Phase 2, a definition was drafted and sent to the members of the expert group. In this final phase, each member was given the opportunity to comment and suggest changes to the proposed definition.

Results

In Phase 1, all invited members of the expert group participated in the survey. After two rounds of Delphi, consensus was reached for 16 components of the WHO definition to remain and for one component (problems associated with life-threatening illness) to be revised (Table 3). In this phase, some comments expressed dislike for the term approach and the adjective impeccable applied to assessment and treatment, in the WHO definition. The group agreed not to delete any component.

Table 2
Members of the Expert Group

Name	Profession	Residence	Country's Income Level ^a
1. Bee Wee	Physician and researcher; head of palliative care research and development, Sir Michael Sobell House in Oxford	U.K.	High
2. Carlos Centeno	Physician and researcher—education in PC. ATLANTES Professor Palliative Care Universidad de Navarra	Spain	High
3. Charmaine Blanchard	Physician—PC; senior lecturer and researcher, University of the Witwatersrand, Johannesburg	South Africa	Upper middle
4. Chitra Venkateswaran	Physician—mental health and PC; founder and clinical director MEHAC Foundation	India	Lower middle
5. Christina Puchalski	Physician—spiritual care; director, GWish	U.S.	High
6. Claudia Burla	Physician—geriatrician; secretary of the board, International Association of Gerontologists	Brazil	Upper middle
7. Cynthia Goh	Physician—chairperson of the Asia Pacific Hospice and Palliative Care Network	Singapore	High
8. Dingle Spence	Physician—PC; regional leader, president Caribbean Palliative Care Association	Jamaica	Upper middle
9. Eduardo Bruera	Physician—PC in cancer; researcher; PC chair, MD Anderson Cancer Center	U.S.	High
10. Emmanuel Luyirika	Physician—regional leader; executive director; APCA	Uganda	Low
11. Esther Cege Munyoro	Physician—PC; coordinator, PC unit, Kenyatta National Hospital, Nairobi	Kenya	Lower middle
12. Hibah Osman	Physician—PC; executive and medical director, Balsam Center, Beirut	Lebanon	Upper middle
13. Jim Cleary	Physician—PC in cancer; researcher; director WHO Collaborating Center in PPSG	U.S.	High
14. Jinsun Yong	Nurse—education in PC; director WHO Collaborating Center for Training in Hospice & Palliative Care	Republic of Korea	High
15. Joan Marston	Nurse—PALCHASE	South Africa	Upper middle
16. John Beard	Physician—epidemiology—Healthy Aging WHO	Switzerland	High
17. Julia Downing	Nurse—professor PC; Makerere—ICPCN	Uganda	Low
18. Katherine Pettus	Political science—advocacy international legal frameworks, access to medicines for PC; advocacy officer IAHP	U.S.	High
19. Kathy Foley	Physician—PC specialist; adviser to IAHP	U.S.	High
20. Liliana De Lima	Psychologist, HC administrator, executive director IAHP	U.S./Colombia	High
21. Lukas Radbruch	Physician—professor PC, University Bonn, Chair IAHP	Germany	High
22. M. R. Rajagopal	Physician—PC advocate, Chair Pallium India	India	Lower middle
23. Mary Callaway	Administrator—Board member IAHP and APCA	U.S.	High
24. Mhoira Leng	Physician—PC development, education; lead for PC Makerere University; and Cairdeas International Palliative Care Trust	Uganda	Low
25. Odette Spruitt	Physician—PC; associate professor, Peter MacCallum Cancer Center, Australasian Palliative Link International	Australia	High
26. Odontuya Davaasuren	Physician—professor PC; Mongolian Palliative Care Society	Mongolia	Lower middle
27. Phillippe Larkin	Nurse, researcher—President of EAPC	Ireland	High
28. Quach T. Khanh	Physician—Ho Chi Minh City Hospital—director palliative care unit	Vietnam	Lower middle
29. Richard Harding	Sociologist, researcher—Director of the Center for Global Health Palliative Care Kings College, London	U.K.	High
30. Roberto Wenk	Physician—PC director—National Palliative Care program FEMEBA	Argentina	Upper middle
31. Roger Woodruff	Physician—founder IAHP; retired professor PC	Australia	High
32. Rosa Buitrago	Pharmacist—dean, School of Pharmacy, University of Panama	Panama	High
33. Sebastiane Moine	Physician—primary PC IPPCN	France	High
34. Stephen Connor	Psychologist, administrator, and researcher, ED WHPCA	U.S.	High
35. Sushma Bhatnagar	Physician—professor PC, AIIMS Institute, New Delhi, India	India	Lower middle
36. Tania Pastrana	Physician, sociologist, and researcher—Aachen University; president, Latin American Association for Palliative Care	Germany/Colombia	High
37. Wendy Gomez-García	Pediatric oncology—Global Pediatric Medicine Collaborator for Haiti & Dominican Republic, St. Jude Children's Research Hospital	Dominican Republic	Upper middle
38. Zipporah Ali	Physician—executive director, KEHPCA	Uganda	Low

PC = palliative care; MEHAC = Mental Health Care and Research Foundation; GWish = The George Washington University Institute for Spirituality and Health; APCA = African Palliative Care Association; WHO = World Health Organization; PPSG = Policy and Pain Studies Group; PURCHASE = Palliative Care in Humanitarian Aid Situations and Emergencies network; ICPCN = International Children's Palliative Care Network; EAPC = European Association for Palliative Care; FEMEBA = Federación Médica de la Provincia de Buenos Aires; IPPCN = International Primary Palliative Care Network; ED = emergency department; WHPCA = Worldwide Hospice Palliative Care Alliance; KEHPCA = Kenya Hospices and Palliative Care Association.

^aPer the World Bank Classification.

Table 3

Components of the WHO 2002 PC Definition as Rated by Members of the Expert Group (N = 38) Phase 1 (Percentages)

Component	Stays As Is	Needs Revision	Delete
Approach	47.2	52.8	0
Improves the quality of life	77.8	22.2	0
Patients and their families	70.1	29.9	0
Problems associated with life-threatening illness	27.8	72.2	0
Prevention and relief of suffering	70.1	29.9	0
Early identification of pain	75	16.7	8.3
Impeccable assessment of pain	33.3	61.1	5.6
Treatment of pain	66.7	25	8.3
Early identification of physical problems	66.7	22.2	11.1
Impeccable assessment of physical problems	33.3	61.1	5.6
Treatment of physical problems	52.8	36.1	11.1
Early identification of psychosocial problems	50	36.1	13.9
Impeccable assessment of psychosocial problems	30.6	58.3	11.1
Treatment of psychosocial problems	38.9	50	11.1
Early identification of spiritual problems	58.3	27.8	13.9
Impeccable assessment of spiritual problems	30.6	55.6	13.8
Treatment of spiritual problems	30.6	52.8	16.6
Provides relief from pain	80.6	11.1	8.3
Provides relief from other distressing symptoms	77.8	13.9	8.3
Affirms life and regards dying as a normal process	75	19.4	5.6
Intends neither to hasten or postpone death	72.3	19.4	8.3
Integrates the psychological aspects of patient care	77.8	16.7	5.5
Integrates the spiritual aspects of patient care	77.8	16.6	5.6
Offers a support system to help patients live as actively as possible until death	72.2	25	2.8
Offers a support system to help the family cope during the patient's illness and in their own bereavement	72.2	22.2	5.6
Uses a team approach to address the needs of patients and their families including bereavement counseling, if indicated	55.6	41.6	2.8
will enhance quality of life	63.9	22.2	13.9
and may also positively influence the course of illness	70	25	5
is applicable early in the course of illness	77.8	13.9	8.3
in conjunction with other therapies that are intended to prolong life such as chemotherapy or radiation therapy	72.2	27.8	0
and includes those investigations needed to better understand and manage distressing clinical complications	16.6	77.8	5.6
	70	19.1	10.9
Additional Items Missing and Suggested by the Core Group	Include	Include With Revision	Do Not Include
Access to controlled medicines for pain relief and PC	80.6	19.4	0
PC also includes the management of acute pain (i.e., after trauma)	11.1	2.8	86.1
PC also includes the management of chronic pain in non-life-threatening diseases and conditions	22.2	2.8	75
PC services should also be available to children, older persons, and vulnerable populations	88.9	8.3	2.8
Applicable to special vulnerable population groups, including refugees and disaster victims, LBGT, and prisoners	27.8	27.8	44.4

WHO = World Health Organization; PC = palliative care; LBGT = lesbian, bisexual, gay, transgender.

In bold: Components that reached $\geq 70\%$ consensus.

Note: The option do not know/not sure was never selected.

For the four additional items (Table 3) not included in the WHO definition, there was consensus to include a statement about access to controlled medicines for pain relief and PC, and one on the provision of PC services to children, older persons, and vulnerable populations. The expert group agreed not to include management of acute pain and of chronic pain in non-life-threatening diseases and conditions.

In Phase 2, 600 invitations were sent, and 412 completed the survey (response rate = 69%; see Disclosures and Acknowledgments section). Ninety-nine respondents were from high-income countries (HICs; 29% of 344 members), 101 from upper middle-income countries (45% of 224 members), 143 from LMICs

(56% of 255 members), and 69 from low-income countries (LICs; 36% of 191 members) (Fig. 2). Participants represented a broad range of backgrounds, including health professionals, caregivers, and patients. There was a strong level of consensus with more than 90% of participants rating mostly or completely agree for all the items in the third Delphi round.¹⁴ A significant proportion of respondents (32%; $n = 131$) submitted additional comments and suggestions, addressing education, community, access to essential medicines, policy, service provision, funding/resources, and research.¹⁴

In Phase 3, members of the core group revised the definition, and based on recommendations from some of its members, we added recommendations directed

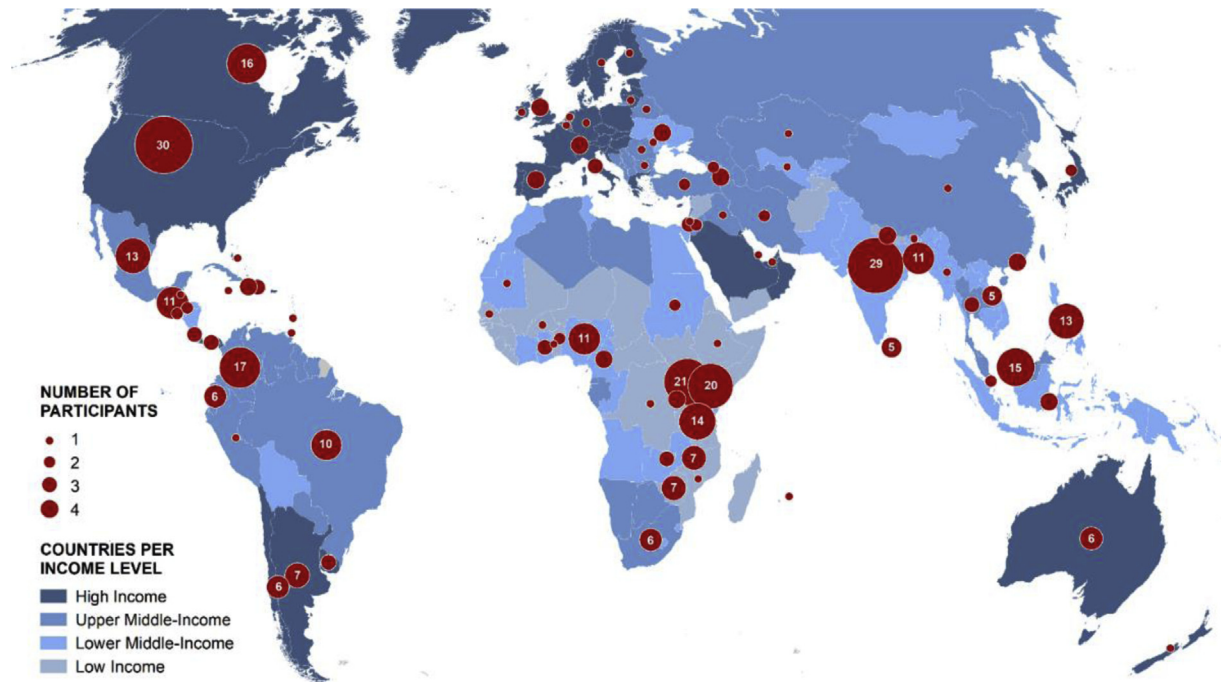


Fig. 2. Countries represented in each income group and number of participants from each country in Phase 2.

to national and local governments around how to achieve PC integration into health systems. The draft was then sent to the expert group from Phase 1. Thirty-six key persons of the initial 38 participated in this final phase. Three rounds of discussions and revisions were carried out until consensus was reached for a final text. The discussion highlighted significant differences and provoked extensive discussion among the participants on the restriction of PC to severe illness, which some participants criticized as too narrow, whereas others felt it excessively broadened the scope. Including a focus on end of life was another area of contention.

The resulting consensus definition was presented to WHO in September 2018 (Table 4). Up until the submission of this article, the WHO had not revised or modified its existing PC definition.

Discussion

Definition

This article describes a consensus-based process to develop a new PC definition that engaged PC stakeholders from around the world. To our knowledge, it is the first time that such a large-scale effort has been implemented to reach a definition for this field. Previous definitions,²² including the WHO definition,³⁰ have been developed by a small group of individuals with no broader input. The definition described in this article resulting from a methodologically sound process reflects the consensus of more

than 450 PC workers from around the globe, located in all geographical regions, representing different fields of work and working in different settings. The definition is well aligned with the 2014 resolution by the World Health Assembly on PC⁶ and reflects the international growth of and transitions in PC over time.

The resulting definition is based on the SHS concept, as put forward by the Lancet Commission. Emphasizing suffering as a mainstay of the new definition allows a further shift from a disease-centered conceptualization to a more person-centered approach to PC. The definition recognizes that PC should be delivered based on need rather than prognosis, is applicable in all care settings and levels, and encompasses both general and specialist care. Increasingly, SHS is replacing older concepts in population-based studies and strategic planning of health care delivery, to identify PC need and monitor effective access for target populations,³¹ and this revised definition is a useful complement to that work.

This consensus-based definition follows a similar structure to the current WHO definitions and is separated into two sections: an initial concise statement and a list of bulleted and more specific components.

A third section was added after participants suggested that a set of recommendations to governments should accompany the definition. These recommendations are directed to national and local governments on how to achieve PC integration into health systems as a component of Universal Health Coverage³² to achieve the sustainable development goals by 2030.³³

Table 4
PC—Resulting Definition From Phase 3

PC is the active holistic care of individuals across all ages with SHS (suffering is health related when it is associated with illness or injury of any kind. Health-related suffering is serious when it cannot be relieved without medical intervention and when it compromises physical, social, spiritual, and/or emotional functioning. Available from <http://pallipedia.org/serious-health-related-suffering-shs/>) because of severe illness (severe illness is a condition that carries a high risk of mortality, negatively impacts quality of life and daily function, and/or is burdensome in symptoms, treatments, or caregiver stress. Available from <http://pallipedia.org/serious-illness/>) and especially of those near the end of life. It aims to improve the quality of life of patients, their families, and their caregivers

PC:

- Includes, prevention, early identification, comprehensive assessment, and management of physical issues, including pain and other distressing symptoms, psychological distress, spiritual distress, and social needs. Whenever possible, these interventions must be evidence based
- Provides support to help patients live as fully as possible until death by facilitating effective communication, helping them, and their families determine goals of care
- Is applicable throughout the course of an illness, according to the patient's needs
- Is provided in conjunction with disease-modifying therapies whenever needed
- May positively influence the course of illness
- Intends neither to hasten nor to postpone death, affirms life, and recognizes dying as a natural process
- Provides support to the family and caregivers during the patients' illness, and in their own bereavement
- Is delivered recognizing and respecting the cultural values and beliefs of the patient and family
- Is applicable throughout all health care settings (place of residence and institutions) and in all levels (primary to tertiary)
- Can be provided by professionals with basic PC training
- Requires specialist PC with a multiprofessional team for referral of complex cases

To achieve PC integration, governments should:

- Adopt adequate policies and norms that include PC in health laws, national health programs, and national health budgets
- Ensure that insurance plans integrate PC as a component of programs
- Ensure access to essential medicines and technologies for pain relief and PC, including pediatric formulations
- Ensure that PC is part of all health services (from community health-based programs to hospitals), that everyone is assessed, and that all staff can provide basic PC with specialist teams available for referral and consultation
- Ensure access to adequate PC for vulnerable groups, including children and older persons
- Engage with universities, academia, and teaching hospitals to include PC research and PC training as an integral component of ongoing education, including basic, intermediate, specialist, and continuing education

PC = palliative care; SHS = serious health-related suffering.

The new definition includes family members and caregivers as the unit of care, thus requiring additional resources from care services, which may be challenging to health care systems with limited resources.

Feedback From Panelists

During the first Delphi round in Phase 1, there was no consensus among the experts on 12 components, but analysis of their comments indicated concerns with form rather than substance. For example, there was no consensus to keep the component *Provides relief of pain*, as the relief cannot be guaranteed, although pain should always be evaluated and managed when present. The experts agreed that the aim is to relieve pain, enhance quality of life, and relieve suffering, but there is no assurance that these will be completely achieved.

Comments from the large number of participants in the second phase of the study highlighted differences among specialized PC professionals working in HIC and in complex settings and those working at the community level in countries with fewer resources. One participant from Australia commented: *... emphasizing care in the community overlooks the current reality that the majority of people (at least in developed countries) die in hospital, where end of life care is often suboptimal and needs support*, whereas another from Nigeria stated: *Integrating palliative care services proactively at the primary and*

community level is supposed to be the bedrock of the services. Many comments underscored the need to implement robust PC training programs for health care professionals both at the undergraduate and specialty levels. Trained professionals are a scarce resource in countries in all income levels. However, even in HIC, a significant percentage of PC is delivered by nonspecialist PC staff, including not only general practitioners and other physicians but also nurses and allied health care professionals. In consequence, the Lancet Commission advocated that all health care professionals caring for severely ill patients should have basic PC training as part of their formal education.⁴

Perceptions

During all the phases of the study, it became clear that participants had significantly different perceptions and interpretations of PC. The greatest challenge faced by the core group was trying to find a middle ground between those who think that PC is the relief of all suffering and those who believe that PC describes the care of those with a very limited remaining life span.

The term that generated the most divergent opinions was severe illness. Severe illness has been defined by the Lancet Commission as any acute or chronic illness and/or health condition that carries a high risk of mortality, negatively impacts quality of life

and daily function, and/or is burdensome in symptoms, treatments, or caregiver stress.^{3,4} Some experts disagreed with the term because it excludes patients with less than severe conditions from access to care, as they think that PC is to relieve all health-related suffering (e.g., including acute trauma). Other experts rejected the term for exactly opposite reasons, as they argued that it broadens the scope too much, with the potential of confusing providers, administrators, policy makers, and funders. Their concern was that the resulting ambiguity surrounding the use of this term would open up PC to treating any illness including acute or transitory conditions. The discussion highlighted that an inclusive term is extremely important, even more so in LICs, where many times patients with other than life-limiting diseases face considerable suffering if they cannot access PC. The members of the core group decided to keep the term severe illness with the addition of a special—but not exclusive—focus on the end of life.

Some participants were critical of the term end of life and felt that the definition was too focused on death and dying. However, of all the vulnerable groups in PC, those facing end of life are the most fragile and the ones with the weakest voices. Health systems—especially in countries with limited resources—tend to leave dying patients on the fringes and not allocate resources for their care. Including specific mention of end of life in the definition serves as a reminder to professionals, policy makers, and funders that patients at the end of life represent an important group requiring health care. The final wording of the definition seemed to present the broadest common denominator for all participants, as consensus was achieved for all statements at the end of the process.

Study Limitations

The definition was developed using an established consensus methodology. We followed the Conducting and REporting DElphi Studies recommendations for consensus building in PC. For example, we provided external validation by asking a number of international PC organizations to review the final version of the definition before publication and dissemination. Some organizations were very supportive, whereas others were quite critical, indicating a lack of agreement on some components of the new definition. The critical responses focused on the scope of the new definition being either too broad or too narrow. This highlights the wide range of practices, perspectives, and understanding of PC around the world and underscores the need to have a consensus-based definition. With this in mind, we considered all critical comments in the final definition, which marks the common ground among different PC settings.

The large group of participants in the second phase of the consensus process was recruited from the IAHPHC membership, which led to a selection bias. Most of the IAHPHC members are located in Africa (25%) and Asia (24%), followed by North America (19%), South America, (12%), Europe (10%), and other regions (10%). Notwithstanding, the IAHPHC is one of the three international PC organizations with members located in all regions of the world. IAHPHC membership is open to PC workers from all fields, including physicians, nurses, psychologists, social workers, spiritual care professionals, and many others.

The consensus panel included a representative selection, with comparable numbers of participants from HICs, middle-income countries, and LICs around the world, rather than being skewed toward the concentration of PC professionals in HIC. The sample reflects the higher met and unmet needs for PC in LMICs.⁴ This is a much broader approach than those used previously for other definitions, including WHOs. The expert group and consensus panel included pediatric and geriatric experts. A major shortcoming is the limited number of patients and caregivers in the development of the definition. The focus of the consensus process was on PC providers rather than patients, although several experts also had experienced PC as caregivers for a family member, and one expert was a cancer survivor. Feedback from these stakeholders is a key feature of the next stage of work on the proposed definition highlighting the need for more research that includes focus group analysis with patients of varying ages (including young people) and caregivers. This would ensure that the definition is understandable and sensitive to the voice of patients.

This study focused on describing the process to develop a consensus-based definition. No qualitative analysis of the participants' perceptions and interpretations was performed. Further analysis of such information will be undertaken.

Dissemination

The IAHPHC is facilitating and encouraging the dissemination and uptake of this work through its global network of PC organizations and members. For example, the definition has been translated by IAHPHC members (using their mother tongues) into Arabic, Chinese, Dutch, Estonian, French, German, Greek, Indonesian (Bahasa), Italian, Japanese, Portuguese, Russian, and Spanish (available at <https://hospicecare.com/what-we-do/projects/consensus-based-definition-of-palliative-care>). Members who contributed to this project in a volunteer basis were given a three-month extension to their membership as a gesture of gratitude for their contribution.

As of November 2019, 180 hospice and PC organizations and academic centers as well as more than a 1000

individuals from countries from all world regions had endorsed and agreed to use the PC definition proposed in this article (<https://hospicecare.com/what-we-do/projects/consensus-based-definition-of-palliative-care/endorsees-list/>).

Conclusion

Developing a consensus-based definition of PC required extensive deliberation, rigorous examination, and thorough testing. It was challenging to find common ground among individuals with long-standing experience in the field of PC who had firmly held positions.

Although the consensus-based definition is not perfect, it creates practice and policy value beyond its intended purpose of defining PC comprehensively and clearly. It provides an opportunity to examine international developments in the conceptualization and practice of PC and to achieve an explicit and shared understanding of that practice across the global community. The new definition is inclusive, encompasses health-system advances, and reflects the opinions and perceptions among a global community of professional health care providers. The new definition is aligned with the recommendations of the Lancet Commission, allowing for future synergy with efforts to implement the recommendations of its report and future implementation activities.

Future research is needed to evaluate the uptake, benefits, and challenges faced by those who use this new definition. This consensus-based definition must be open to critical discussion that includes patients and caregivers as well as providers. To this end, IAHPCC continues to collate all feedbacks in what will be a continuous process of adapting the definition of PC to the ever-changing realities of patient needs.

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Ethical approval: The project did not involve any therapeutic intervention. Ethical aspects of the consensus project, for example, on data protection, were discussed extensively among the board of directors of IAHPCC. The project plan was submitted to the Ethics Committee at the Fundación Federación Médica de la Provincia de Buenos Aires in Argentina by one of the lead authors (R. W.) and was approved with no ethical issues raised.

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