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PALLIATIVE CARE

HOW CAN WE RESPOND TO 10 YEARS OF LIMITED PROGRESS?

Richard Harding
Asmus Hammerich
Anna Peeler
Oladayo Afolabi
Katherine Sleeman
Didi Thompson
Maha El Akoum
Nahla Gafer

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FOREWORD

Clinicians, researchers and policymakers are trying to respond to the rapidly aging global population and the increasing prevalence of chronic diseases. This report brings into stark relief what this means for health systems, patients and their families. The number of people dying with health-related suffering is predicted to nearly double from 26 million per year to 48 million by 2060. This increase will be greatest in low- and middle-income countries, for people over the age of 70, and those with dementia, cancer and cerebrovascular disease. This avoidable suffering leads to an unnecessary burden for patients and families, but it also leads to unnecessary hospital admissions and overly intensive care for already strained health systems.

In 2014, World Health Assembly (WHA) Resolution 67.19 called for Member States to develop, strengthen and deliver palliative care across all ages as an essential component of universal health coverage. Despite this, only about 14 percent of all global palliative care need is met, and health systems around the world are unprepared to meet the growing need.

Palliative care is holistic, person-centered care focused on improving quality of life for people of all ages with life-limiting and life-threatening illness and the people who care for them. Palliative care strives to prevent and relieve health-related suffering through early identification, assessment and treatment of pain and other physical, psychosocial and spiritual problems (existential distress, disturbance of meaning or purpose in life). A common misconception is that palliative care is for people who are dying or those with cancer, but this type of care is for anyone with life-limiting or life-threarening illness experiencing health-related suffering, and can be provided alongside curative and intensive treatment.

Evidence supporting various models and components of palliative care should guide all decisions and local, national and international efforts to make targeted improvements. Models of specialist, generalist, pediatric, public health, nurse-led, rehabilitative and bereavement-focused palliative care have been shown to improve patient, caregiver, and health-system centered outcomes for many populations and contexts.

This report describes the limited progress that has been made since WHA Resolution 67.19, and outlines priority actions to expand access to, and quality of, palliative care globally. Using the World Health Organization's conceptual model of palliative care development, we make recommendations in each of the six essential components, including: provision of palliative care through integrated health services; use of essential medicines; education and training; research; health policies; and empowering people and communities. These could work together to ensure access to timely and effective palliative care for all children and adults with life-limiting illness.

Palliative care as part of comprehensive care for children and adults strengthens health systems and is an essential, effective and cost-efficient component of achieving universal health coverage. Unless urgent, evidence-based, co-ordinated action is taken, countries, health systems and communities will be unprepared to meet growing palliative care demand. Millions of people around the world will experience preventable suffering, and the wider health system delivery will be compromised.

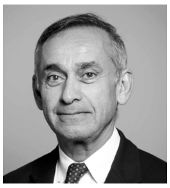
We commend this report. Although there has been evidence of novel and locally appropriate innovations to advance delivery of quality palliative care, this is not yet adequate to achieve universal coverage. The recommendations in this report offer a way to provide effective, cost-sustainable palliative care for all those who need it, and to achieve the universal health coverage goal of outcomes-focused palliative care as an essential health service.

Richard Harding

Richard Harding
Interim Dean, Florence Nightingale Faculty of Nursing, Midwifery, and Palliative Care at King's College London

AHammerich

Dr Asmus Hammerich
Director, Noncommunicable Diseases & Mental Health (NMH) & Acting Director, Healthier Populations (HPD) WHO Eastern Mediterranean Regional Office (EMRO)



Professor Lord Ara Darzi
Director of the Institute of Global Health Innovation and Paul Hamlyn Chair of Surgery at Imperial College London; Executive Chair, WISH

EXECUTIVE SUMMARY

Palliative care is holistic, person-centered care for children and adults living with life-limiting and life-threatening illness, and is also for the friends and family who care for them. It can be provided by multidisciplinary teams of specialists or non-specialists according to case complexity and available resources.

Many people with life-limiting illness face significant, multidimensional burdens of health-related suffering, including pain, fatigue, dyspnea, depression, psychosocial distress and delirium. The people who care for them can also have burdensome physical, psychological, social and spiritual problems such as weight loss, insomnia, anxiety, complicated grief, impaired social relationships and disturbance of meaning in life. These often require high healthcare use, including unplanned admissions and overly intensive treatment, burdening people and health systems with high costs. By 2060, the number of people dying with serious health-related suffering across all age groups is expected to increase by 87 percent.

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Ten years ago, World Health Assembly (WHA) Resolution 67.19 on Palliative Care called for global strengthening of quality, accessible palliative care service for people of all ages as an essential component of universal health coverage (UHC). The WHA Resolution 67.19, and the inclusion of palliative care as an essential health service under UHC and the Declaration of Astana at the Global Conference on Primary Health Care, were in response to unmet, and growing need for palliative care. Evidence suggests that progress has been extremely slow in expanding access and improving quality of palliative care services globally, particularly in low- and middle-income countries (LMICs).

To address the growing demand, and correct the lack of progress on the recommendations of WHA Resolution 67.19, it is crucial to use evidence for palliative care interventions, models and delivery. This report includes multiple case studies that highlight innovative and transformative models of palliative care. They serve as exemplars for what targeted intervention can achieve in palliative care delivery, education and training, outcome measurement, cultural adaptation, needs assessment and policy development.

The report details the persisting and worsening inequities in access to and quality of palliative care services globally. Geographic, social, cultural and health-literacy related inequities in access to and quality of palliative care services persist. Drivers include access to essential medicines such as opioids, clinician and public reluctance to address issues around disease progression, and presumptions that palliative care is solely for people with cancer or those who are close to dying.

The report concludes with a warning that, unless urgent, evidence-informed, co-ordinated action is taken, the benefits of palliative care will not be achieved under UHC to meet the growing demand for care. We recommend priority action areas to expand access to timely and effective palliative care for children and adults globally. Based on the World Health Organization's (WHO's) six components of palliative care development, these priority areas include: developing national palliative care policies that prioritize evidence-based guidelines and sustainable funding; empowering and facilitating community action in service development, research, and peer support; improving equal access to palliative care services for people of all ages without sacrificing quality, paying particular attention to LMICs and vulnerable populations; expanding education and training for both specialists and non-specialists at all levels; ensuring access to essential medicines; and building research capacity.

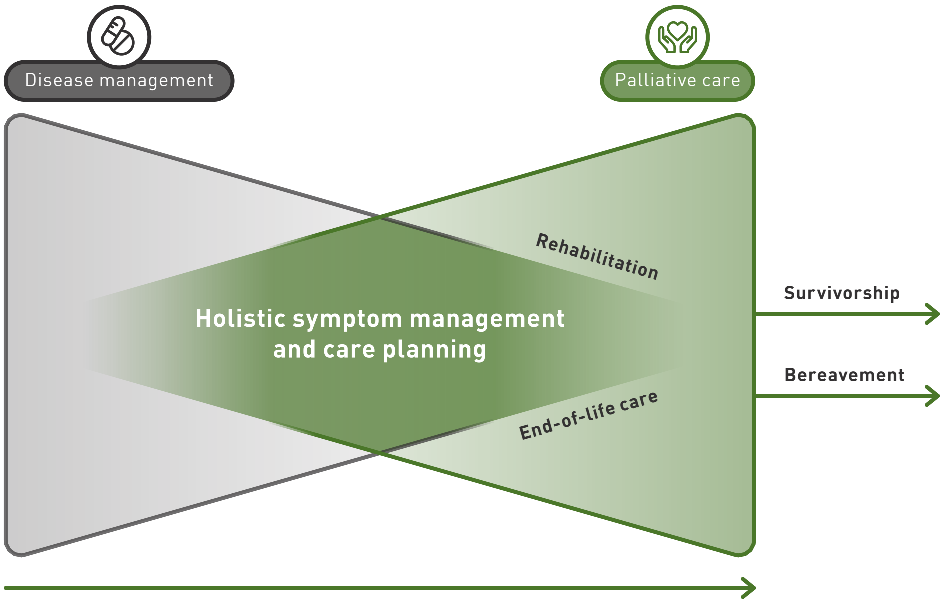
PALLIATIVE CARE:
A RESPONSE TO SUFFERING

WHAT IS PALLIATIVE CARE?

Palliative care is holistic,[1] person-centered[2] care for children and adults living with life-limiting illness, and for the people who care for them. It prevents and relieves health-related suffering by means of early identification, assessment and treatment of pain and other physical, psychosocial and spiritual problems.[3] It includes (but is not limited to) end-of-life care.[4–6] Further consensus on the definition has expanded the problems addressed by palliative care to include "serious health-related suffering due to any severe illness."[7] Palliative care for children holistically cares for the child's body, mind and spirit from diagnosis of life-limiting illness regardless of treatment status and supports their family members.[8]

Palliative care involves identifying person-centered goals and preferences, and holistic assessment and management of physical, psychological, social and spiritual suffering as illness progresses to end-of-life care and into bereavement.[9]

There is a common misconception that palliative care is only for people who are close to dying.[10] Palliative care addresses holistic concerns at any stage of serious illness and can be integrated with aggressive or curative treatment across the care continuum.[11] Receiving palliative care does not mean that a person is 'giving up' on treatment.[12] The figure below shows how palliative care and disease-oriented care overlap and can be provided together.[13, 14]



Source: International Children's Palliative Care Network (2024)[15]

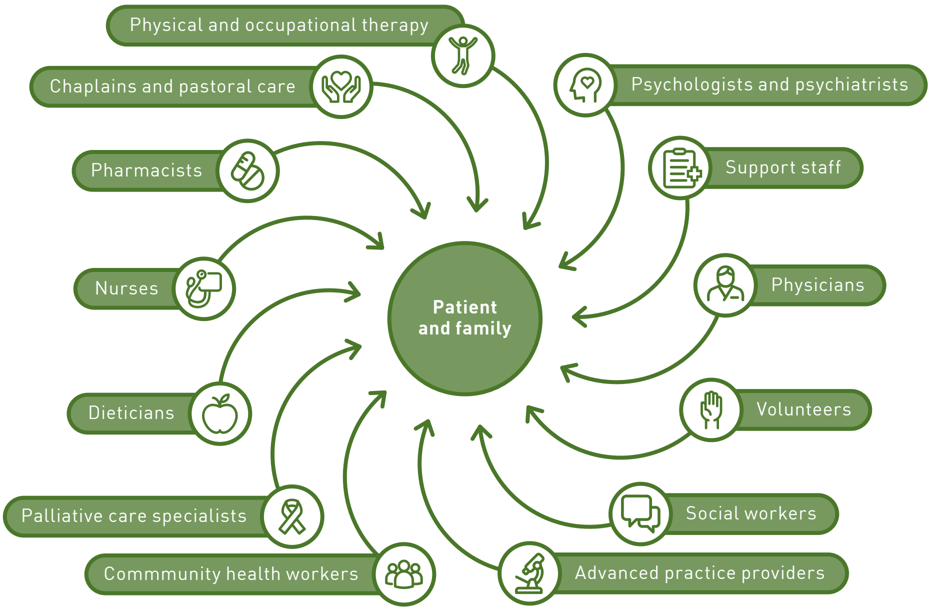
A variety of terms is used to describe delivery of palliative care in different contexts, by different healthcare specialties, and at different stages of disease trajectory. Some refer to 'hospice', 'end-of-life' or 'terminal' care to distinguish care that takes place when a person is close to death.[16] We use the term 'palliative care' in this report to encompass all holistic, person-centered care for people experiencing health-related suffering due to a life-limiting illness.

WHO DELIVERS PALLIATIVE CARE?

Palliative care can be provided by specialists or non-specialists of any discipline, according to case complexity and available resources. Specialists, such as palliative care physicians, nurses, or allied health professionals with specialized training in holistic assessment, symptom management and communication, can serve as the palliative care experts in a patient's healthcare team. They work in conjunction with other providers to prioritize quality of life and the patient's values. Non-palliative-care specialists and generalists, or clinicians working in teams that do not focus solely on palliative care (for example, those working in primary care, pediatrics, oncology or cardiology) can provide some core palliative care services alongside usual care for their patient populations. Caregivers and community members also provide immense support and can augment palliative care delivery from health services.[17]

As palliative care involves treating the 'whole person' and the people who care for them, palliative care teams should be interdisciplinary.

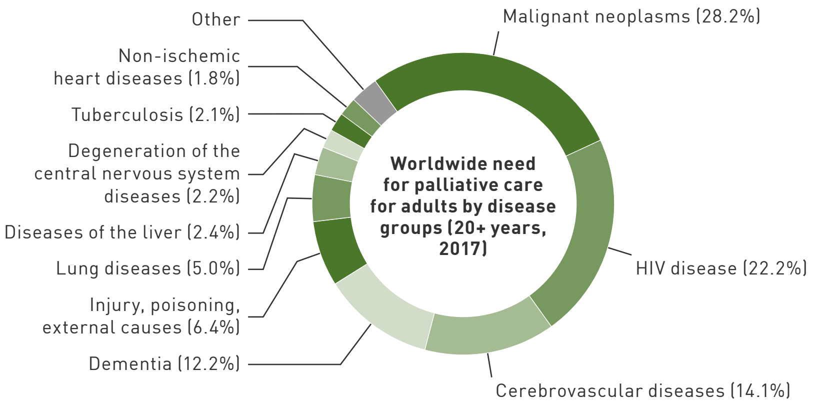
As palliative care involves treating the 'whole person' and the people who care for them (that is, assessing and managing their physical, psychological, social and spiritual symptoms and concerns), palliative care teams should be interdisciplinary.[18] Often teams are made up of healthcare professionals and volunteers from many disciplines, as seen in the figure below. Regardless of specialization, all healthcare

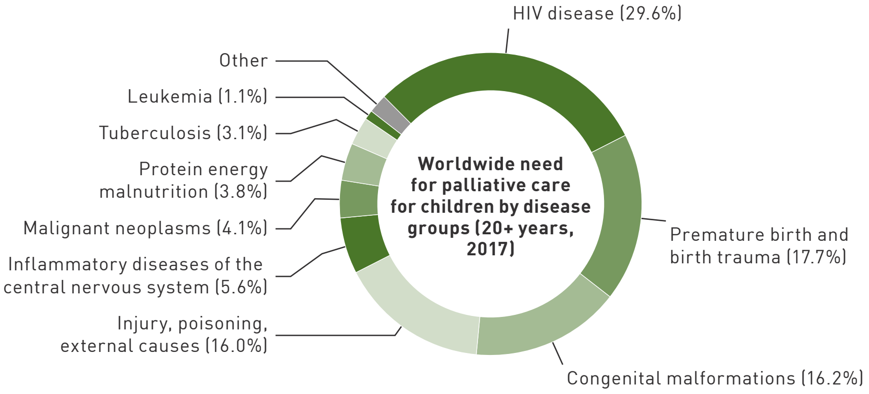


professionals who are likely to interact with people with life-limiting illness require some core palliative care training and referral pathways to escalate complex cases to palliative care specialists.[19, 20]

WHO COULD BENEFIT FROM PALLIATIVE CARE?

Globally, over 60 million people per year experience serious health-related suffering that could be prevented with palliative care intervention.[21] The health conditions most commonly requiring palliative care in adults and children can be seen in the following figures.[22]

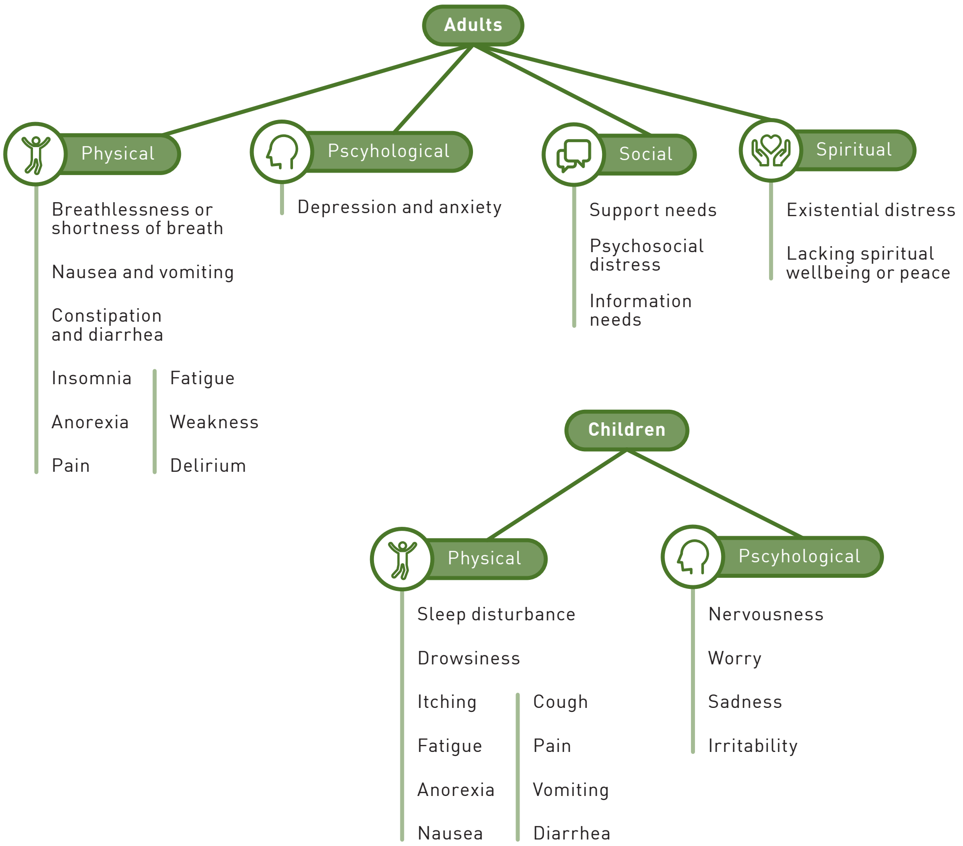




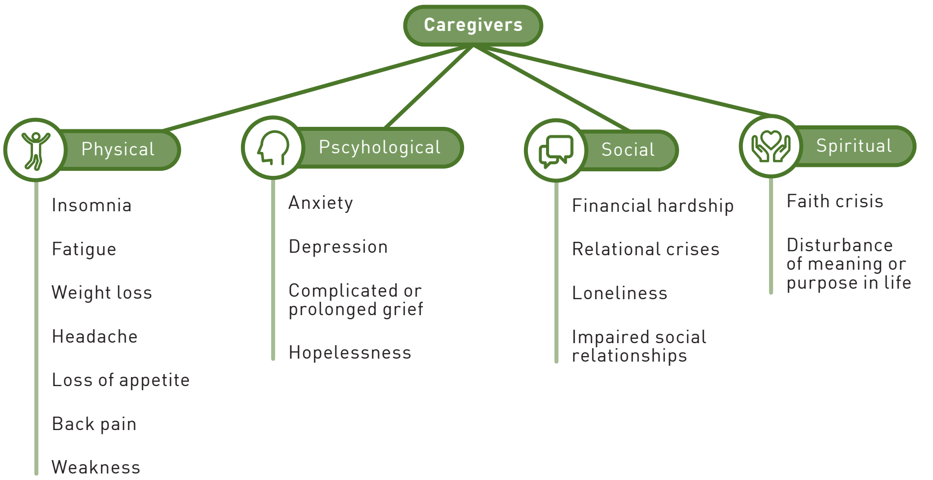
Note: Diseases with an incidence under 1% have been grouped into 'Other'. These are, for adults: renal failure, chronic ischemic heart diseases, musculoskeletal disorders, leukemia, atherosclerosis, protein energy malnutrition, inflammatory diseases of the central nervous system, congenital malformations, hemorrhagic fevers, and premature birth and birth trauma; and for children: degeneration of the central nervous system diseases, diseases of the liver, cerebrovascular diseases, renal failure, non-ischemic heart diseases, musculoskeletal disorders, lung diseases, atherosclerosis, hemorrhagic fevers and dementia.

Source: Global Atlas of Palliative Care, 2nd Edition (2020)

The multidimensional symptoms and concerns people with these and other conditions experience are often described as "palliative care-related problems" as they significantly impact quality of life and are the target of palliative interventions.[23] They are seen in varying degrees across diagnostic groups, ages and populations.[24,25]



Sources: Moens K et al. (2014)[26] and Wolfe J et al. (2015)[27]



Sources: Moens K et al. (2014),[28] Choi S and Seo J (2019),[29] Miquel P et al. (2024),[30] Abdulla S et al. (2024),[31] Postavaru GI et al. (2021),[32] Nikfarid L et al. (2020)[33]

The burden of caring for a loved one with life-limiting illness can be extremely challenging. Similar to the people they care for, caregivers can have burdensome physical, psychological, social and spiritual problems (see previous figure) related to their role, but they often receive less support from health and social care services.[34] In addition to the acute stress of the disease, caregivers face grief, uncertainty, and distress through to the bereavement phase.[35]

For many people, these problems are preventable with palliative care intervention.[36–38] Palliative care needs and people's priorities differ according to diagnosis, prognosis, cultural background, location, family support and resource availability. Therefore, assessment of and response to needs should be context-specific and culturally informed.[39]

AN ESSENTIAL COMPONENT OF CARE UNDER UNIVERSAL HEALTH COVERAGE

Palliative care and relief of suffering are often overlooked in public and global health responses.[40,41] In 2014, WHA sought to take steps to correct this historic oversight by officially calling on Member States to develop, strengthen and deliver palliative care across all ages as an essential component of UHC (see WHA Resolution 67.19 on Palliative Care in the Appendix).[42]

> **"Universal health coverage means that all people have access to the full range of quality health services they need, when and where they need them, without financial hardship. It covers the full continuum of essential health services, from health promotion to prevention, treatment, rehabilitation, and palliative care across the life course."**
>
> **World Health Organization**

In 2017, the continuum of essential health services to be provided under UHC was updated to include "health promotion, prevention, treatment, rehabilitation and palliative care". In 2018, the Declaration of Astana, formulated at the Global Conference on Primary Health Care, solidifed palliative care as an essential component of primary healthcare.[43] Today, these documents are the foundation of the global health mandate that palliative care is an essental service that should be delivered to all those who need it. A timeline of key palliative care milestones can be seen on the following page.

1967: Dame Cicely Saunders opens St. Christopher's in the UK, the first modern hospice

1970s

1974: Dr Balfour Mount, a surgical oncologist from McGill University, coined the term 'palliative care' to distinguish it from hospice care

1978: Edmrc opens in the United States as the first hospice specifically for children

1980s

1980: The International Hospice Institute, which later became the International Association for Hospice and Palliative Care, is established

1987: The UK becomes the first country to officially recognize palliative care as a medical specialty

1988: The UN Convention on the Rights of the Child asserts that children have a right to high-quality treatment of illness

1989: The WHO publishes the first guidance on cancer pain relief and palliative care

1990s

1990: The WHO recognizes palliative care as a distinct specialty dedicated to relieving suffering and improving quality of life for patients with life-limiting illness

1998: The WHO defines palliative care for children and develops guidelines for cancer pain and children's palliative care

2000s

2005: The International Children's Palliative Care Network is established

2008: The Worldwide Hospice Palliative Care Alliance is founded

2010s

2013: The WHO releases its first list of essential medicines for pain and palliative care

2014: World Health Assembly Resolution 67.19 is adopted; First Global Atlas of Palliative Care is published

2015: The Inter-American Convention on the Rights of Older Persons declares that palliative care is a human right

2017: The Lancet Commission on Palliative Care and Pain Relief is created; Universal Health Care definition is updated to include palliative care as an essential component across the lifespan

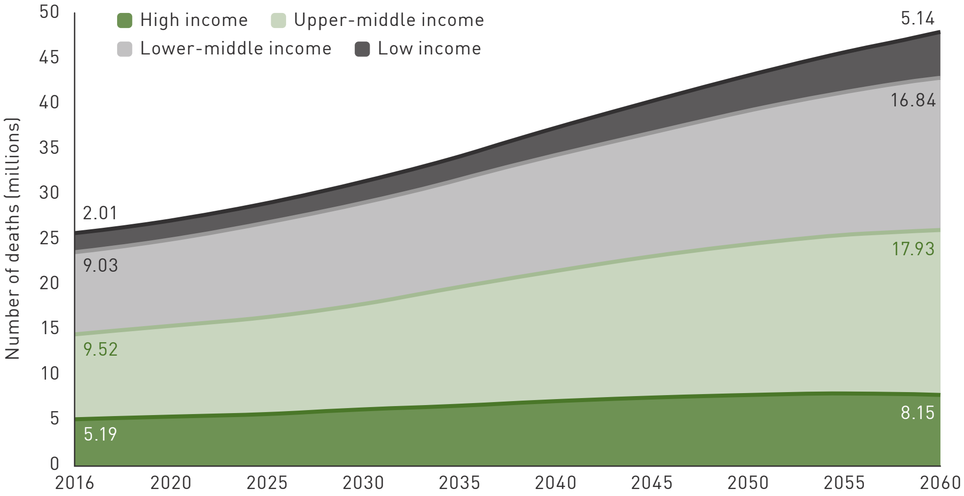
2018: The Astana Declaration makes palliative care the fifth essential pillar of primary care

GROWING NEED AND AN URGENT CALL TO ACTION

As the global population ages and the burden of disease shifts toward chronic diseases, serious health-related suffering is predicted to increase rapidly in the coming years.[44,45] By 2060, the number of people dying with serious health-related suffering across all age groups is expected to increase by 87 percent. The most marked increase is expected in people over the age of 70, people with dementia, cancer, and cerebrovascular disease, and most drastically, for those in LMICs.

The following two figures show the projected increase in the number of people dying with serious health-related suffering by: first, country-income group; and second, diagnosis over the next four decades. In LMICs, nearly 20 million more people will die experiencing serious health-related suffering in 2060 than in 2016, an increase of 155 percent. By 2060, more than 80 percent of those dying with serious health-related suffering will be in LMICs, with the most rapid growth in the Eastern Mediterranean and African regions.[46] This highlights the imperative to expand access to high-quality palliative care to equitably meet global need.

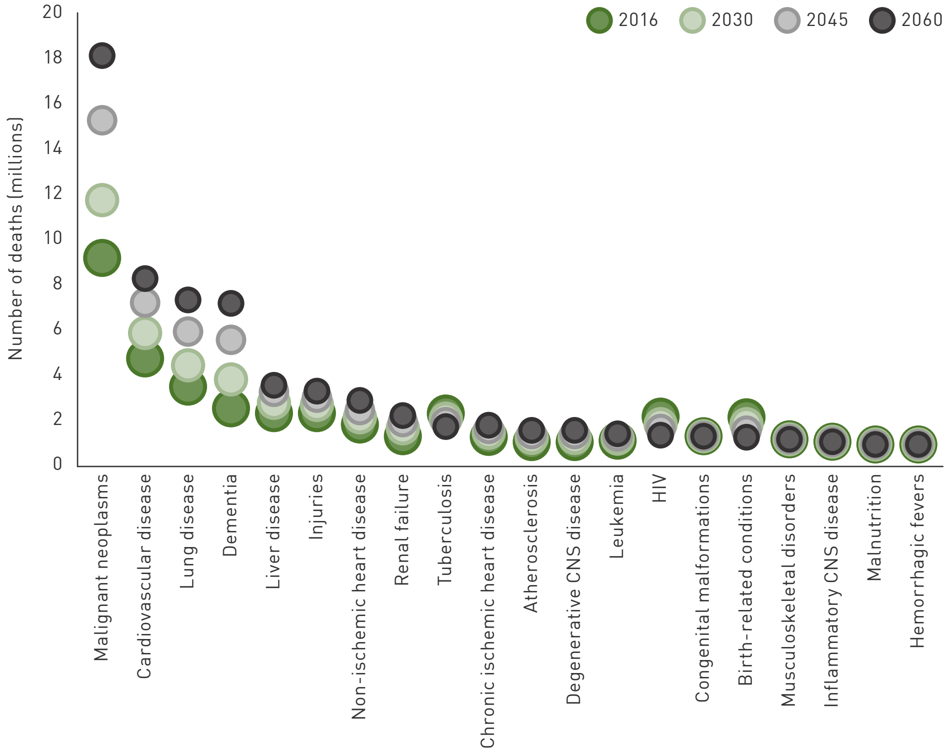
Projected increases in deaths with serious health-related suffering by country-income group



Source: Sleeman et al. (2019)

Despite the growing need for palliative care, the introduction of WHA Resolution 67.19 and the inclusion of palliative care as an essential health service under UHC, evidence suggests that progress has been extremely slow in expanding access and improving quality of palliative care services globally, particularly in LMICs.[47] Globally, only 14 percent of people who would benefit from palliative care receive it. This disparity is even worse in children, with less than 3 percent of those in need receiving palliative care.[48,49] In some cases, global visibility of palliative care remains poor. Notably, reporting on palliative care was absent in the *Tracking Universal Health Coverage: 2023 Global Monitoring Report*.[50]

Projected increases in deaths with serious health-related suffering by disease



Source: Sleeman et al. (2019)

Around the world, many emergency departments and acute care hospital beds are occupied by preventable hospitalizations of people in the last year of life. This is also despite evidence that most people wish to die at home, and that it is more cost-effective to deliver care that addresses their needs outside of acute care settings.[51–55]

In spite of global efforts over the last decade, disparities in access to palliative care services persist and will continue to worsen without concentrated, co-ordinated effort.[56] All people, regardless of age, disease condition, setting or ability to pay, should have access to health services, including palliative care.[57,58] Palliative care is an ethical responsibility for health systems, and equitably eliminating preventable suffering resulting from serious illness is a moral imperative.[59,60]

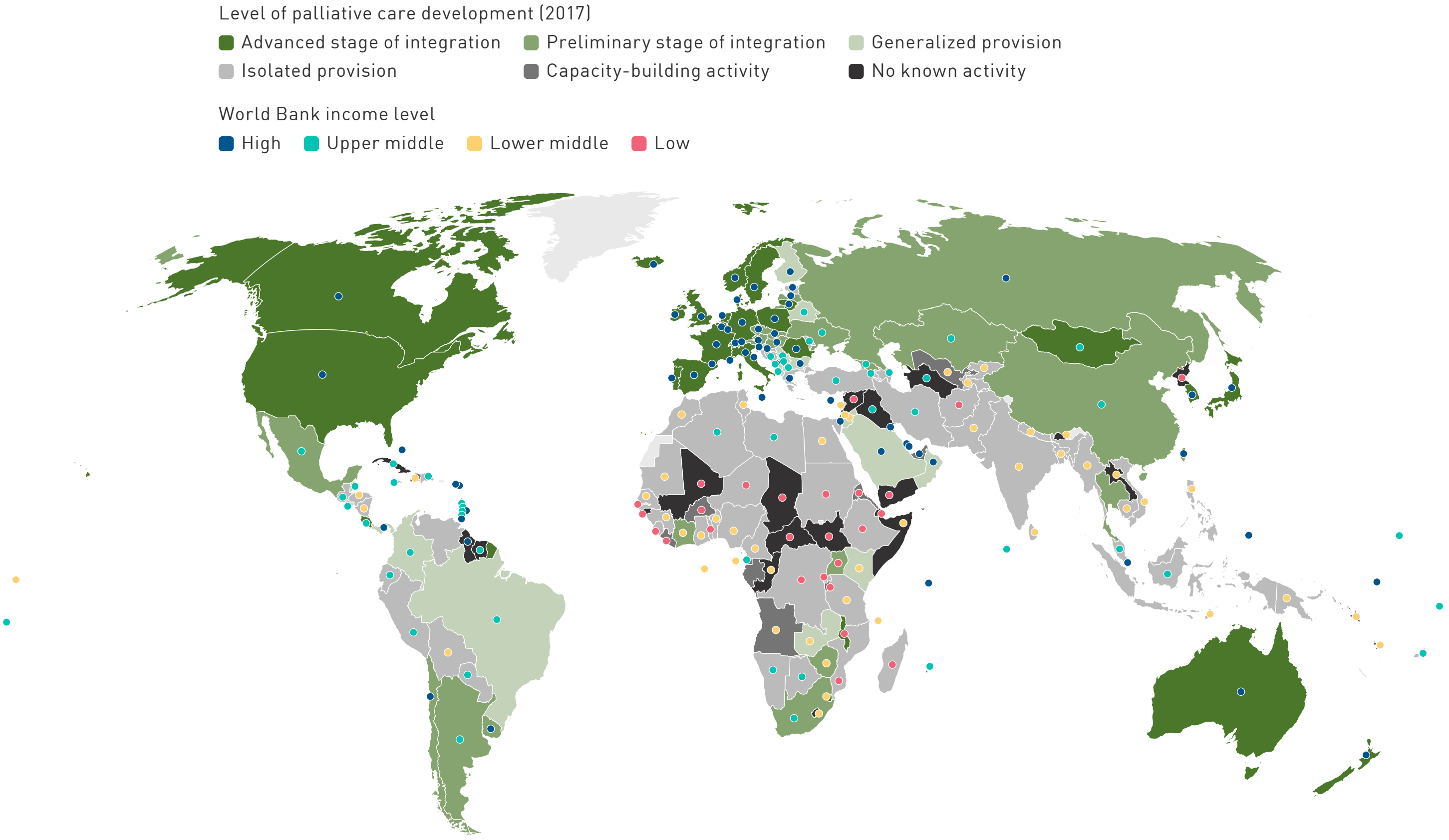
GLOBAL PALLIATIVE CARE INEQUITY AND BARRIERS TO EXPANDING ACCESS

Since WHA Resolution 67.19 on Palliative Care, progress in expanding access to and quality of palliative care services has been alarmingly slow and inequitable. Barriers to service take-up, resource limitations, poor visibility and deep-seated geographic, social, economic, political and environmental determinants of health create and exacerbate inequities.[61,62]

GEOGRAPHIC INEQUITY

The Global Atlas of Palliative Care, a periodic report on the status of palliative care worldwide, disseminated by the Worldwide Hospice Palliative Care Alliance and WHO, has consistently demonstrated global inequities in access to and integration of palliative care.[63] By the end of 2017, 30 countries (15 percent of 198 countries surveyed) had achieved advanced integration of palliative care services. Also, 47 countries (24 percent) had no known palliative care activity, and 65 (33 percent) had only isolated palliative care provision, representing more than half of the world's population with severely or entirely limited access to palliative care (see map below).[64] In 2021, a WHO global monitoring report about national capacity to prevent and control non-communicable diseases found that palliative care was generally

Palliative care development by country and World Bank income level in 2017

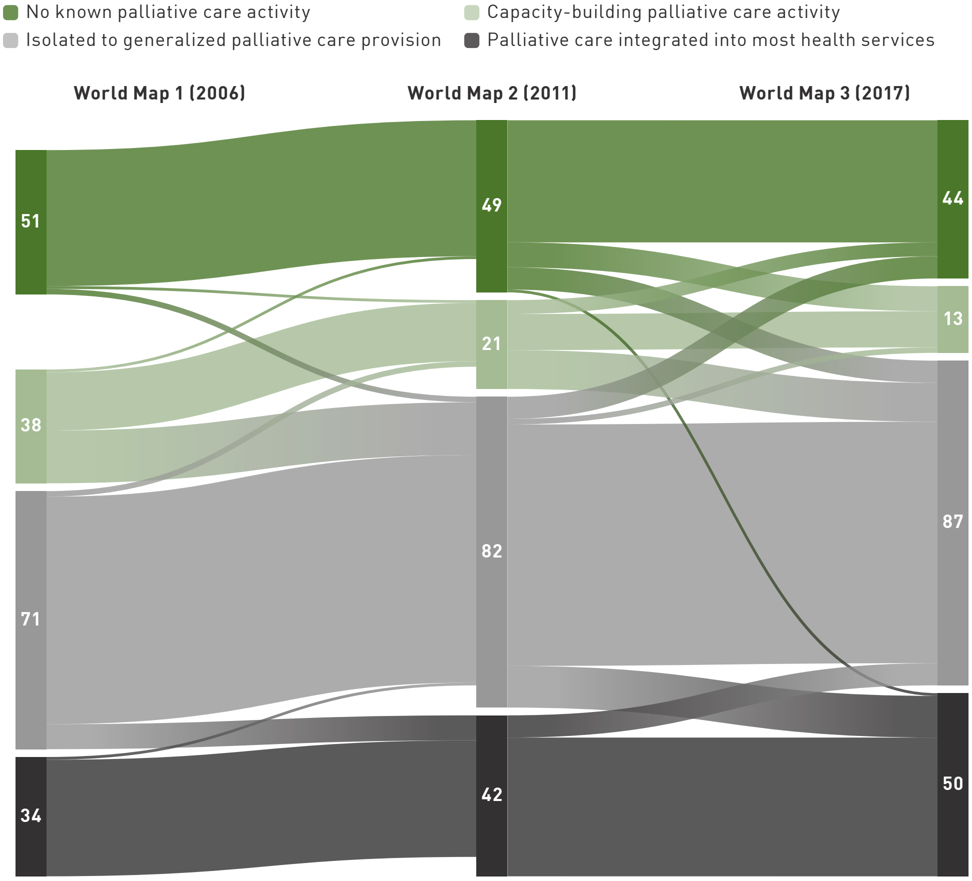


Source: Clark et al. (2020)

available (reaching at least 50 percent of patients in need) in 43 percent of countries, most of which are high-income.[65] The disparity between need and availablity of services is drastic in LMICs, where 80 percent of people with palliative care needs live, and where access to palliative care services is severely limited.[66] Mapping by the International Children's Palliative Care Network shows severe disparities in access to pediatric palliative care services, particularly in LMICs.[67]

The following figure shows that, between the Global Atlas surveys in 2006, 2011 and 2017, countries moved between the categories of palliative care development. While there has been net improvement globally over that period, upward movement has been modest. Furthermore, 23 countries moved down a category between 2011 and 2017, showing a relapse of palliative care development, which has been most prevalent in African countries.[68, 69]

Longitudinal changes in palliative care development category (2006–2017)



Source: Clark et al. (2020)

Similarly, growth of education and training opportunities for healthcare professionals in palliative care is slow, patchy and uncoordinated. Previous mapping has shown the variability in inclusion of core palliative care competencies in healthcare professionals' curriculums.[70–72] While there are excellent course offerings in LMICs,[73] specialist palliative care training is mostly offered at institutions in high-income countries.[74] Correcting disparities for adults' and children's palliative care has been attempted by developing educational standards, audit tools and Massive Open Online Courses (MOOCs – free online courses available to all), however, take-up has been slow.[75, 76]

CASE STUDY 1. INNOVATIONS IN PALLIATIVE CARE EDUCATION FOR HEALTH PROFESSIONALS

Palliative care development at country and local levels depends largely on resource availability. In the last decade, the emergence of Massive Open Online Courses (MOOCs) has expanded access to palliative care education for health professionals who otherwise would not have the opportunity.[77]

- The End-of-Life Nursing Education Consortium in the US has educated more than 1.5 million nurses and allied health professionals in 114 countries in symptom assessment, management and communication. This significantly improves palliative care knowledge and confidence in delivering care for attendees.[78,79]
- The Oman Cancer Association offers a four-part palliative care program in a region where the quality of death index is the worst in the world. This program has taught more than 400 healthcare professionals from 12 countries in the Middle East and North Africa basic and advanced prinicples of palliative care delivery, leadership and research.[80]
- The International Children's Palliative Care Network's elearning program offers free pediatric palliative care training, and has been accessed by more than 15,000 health professionals from 191 countries.[81]

While these initiatives improve health professionals' knowledge, skills and attitudes toward palliative care, more research is needed to quantify the effect of palliative care education on patient outcomes, and to determine which models are most effective.[82–85]

SOCIAL INEQUITIES

Multiple factors contribute to inequalities in provision of, and access to, palliative care within countries – even in high-income countries.[86] Demographics, socioeconomic position, rurality, health literacy and educational attainment, disease condition and severity, and insurance status impact a population's access to high-quality palliative care services.[87] Evidence from the UK, US and Canada demonstrates that people living in the most deprived or rural areas had worse access to, and lower quality of palliative care.[88–90] They were also more likely to receive aggressive end-of-life care and die in an acute care hospital than those living in the least deprived areas.[91,92] Similarly, people from racial and ethnic minority groups are less likely to engage in advance care planning discussions (about future care preferences) and receive palliative and hospice care. They are also more likely to receive aggressive treatment at the end of life.[93] Access and outcomes are even worse for people experiencing homelessness[94] and people in prisons.[95]

CASE STUDY 2. REGIONAL PALLIATIVE CARE NEEDS ASSESSMENT IN COLOMBIA

Palliative care clinicians, researchers and advocates in Colombia have adapted WHO's set of actionable indicators originally developed for country-level evaluations to assess the level of palliative care development in each of its 33 regions. They found disparate levels of palliative care development by region (from none at all to very developed) and that services were highly concentrated in urban, densely populated areas.[96] They then developed a policy plan based on their findings to equitably expand access to palliative care for all ages using participatory action research methodology to engage a wide range of stakeholders (patient representatives, journalists, health professionals, government entities, insurance companies, universities and drug regulatory authorities) from around the country. Through this process, they identified a series of strategic actions tailored for each region, and the country as a whole, that focus on integrating and diversifying palliative care services, improving opioid access, securing funding, implementing an evidence-based regulatory framework and assessing and improving person-centered outcomes.[97]

MISCONCEPTIONS ABOUT PALLIATIVE CARE

Misconceptions about palliative care among the public and healthcare professionals alike continue to limit access for children and adults with life-limiting illness, and their families.[98] The association of the word 'palliative' with death, dying, loss of control and abandonment of hope is often cited.[99] The stigma of the issues surrounding death can be more pronounced and harmful for some ethnic groups and cultures.[100] For children and their parents, this misunderstanding can be even more drastic due to inherent uncertainty in pediatric diagnoses, avoidance of discussions about dying, and a lack of understanding of what pediatric palliative care entails.[101, 102] One survey of parents of children seen at an oncology clinic in Lebanon found that only 17 percent had heard of palliative care and 2 percent had accurate information about it, yet 90 percent supported it when given a brief description.[103] This fear or ignorance of palliative care can be a barrier to acceptance of and referral to palliative care services.[104]

Misconceptions about palliative care among the public and healthcare professionals alike continue to limit access for children and adults with life-limiting illness, and their families.

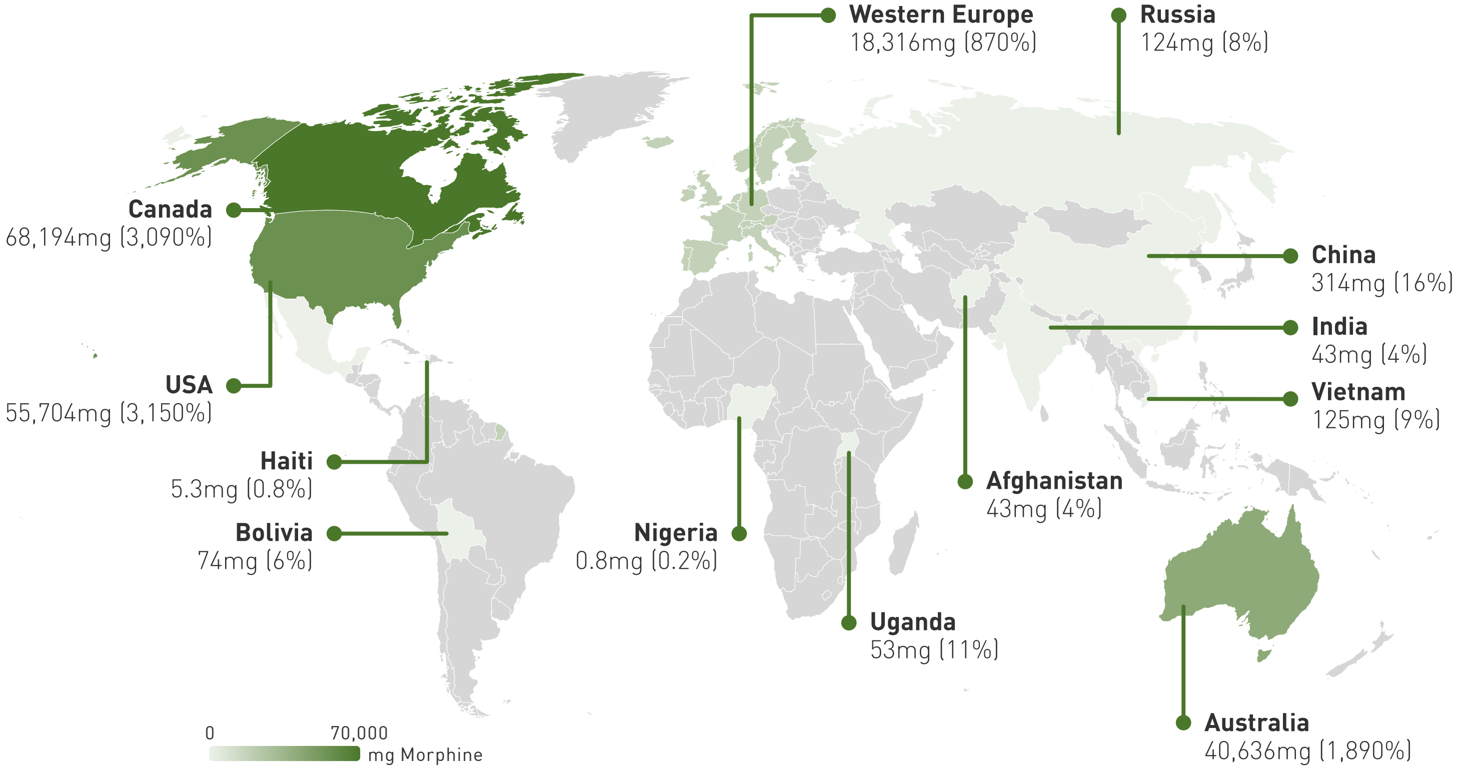
Palliative care take-up is also negatively impacted by misconceptions that palliative care is mainly associated with cancer.[105] Evidence shows that adults and children living with cancer are more likely to receive palliative care, and experience it earlier in their disease trajectory (more than 90 days before death) compared to those with other non-cancer conditions.[106, 107] In one Australian study, 69 percent of patients with cancer received specialist palliative care in the last year of life compared to only 14 percent of people who had died with non-cancer conditions.[108] Despite lower palliative care take-up, people with non-cancer conditions have persisting palliative care needs and many could benefit from palliative care intervention.[109, 110]

The COVID-19 pandemic highlighted the need for palliative care in infectious diseases and pandemic preparedness.[111] This inequity highlights the need to normalize palliative care use when appropriate for people with non-cancer conditions.

OPIOID AND ESSENTIAL MEDICINE AVAILABILITY

Opioids are effective, often inexpensive essential medicines that are crucial for pain and symptom control for adults and children.[112] However, unequal distribution of opioids has caused enormous, unnecessary suffering.[113] A 2023 International Narcotics Control Board report suggested that 19.8 percent of the global population consumed 86.1 percent of morphine produced globally.[114] As seen in the map below, opioid consumption remains inequitably concentrated in high-income countries in Australasia, North America and Western Europe. Other regions have insufficient access to address the medical needs of their populations. This (compounded by complex political, legal and cultural factors) has led to a surplus supply of opioids (both legally and illegally produced and distributed) in some high-income countries, and an epidemic of abuse, dependence and overdose. Meanwhile, most of the world's population in LMICs face unnecessary suffering due to inadequate supply of opioids for therapeutic use in pain and symptom control.[115]

Global distributed opioid morphine equivalent and the percentage of estimated need met



Source: Knaul et al. (2018)[116]

The reasons for the unequal distribution of opioids globally are complex and multifaceted. Before 2018, a critical analysis found that the International Narcotics Control Board activities had focused on illegal drugs, abuse and dependency with less attention to therapeutic use.[117] While there is a need for limiting illegal distribution and misuse of opioids, correcting and ensuring the balance between appropriate medical access to controlled medicines and prevention of abuse is essential in safeguarding populations and reducing suffering. Also inequities can be exacerbated in LMICs due to their limited purchasing power, which can make opioid analgesics unnecessarily expensive, and the fear of illegal trafficking causing overcompensation with total bans on substances.[118] Additional barriers include: an absence of training for healthcare workers;[119] patients' and families' fear of addiction; healthcare workers' fear of prosecution;[120] cultural and religious attitudes toward pain management and opioids;[121] restricted financial resources; and issues in sourcing substances.[122–124]

SPIRITUAL CARE AND RELIGION

With its focus on holistic assessment and care, spiritual support is an integral component of palliative care, yet it is often neglected. This type of care seeks to meet the needs of adults and children of all religious and cultural backgrounds according to their preferences.[125, 126] Death and dying are often accompanied by religious and cultural rituals that bring meaning and comfort to patients and families, and religion often impacts on people's goals, preferences and values for care.[127, 128] Immigration and forced migration have made populations more diverse, necessitating a more multicultural approach to the spiritual component of palliative care. Healthcare providers may lack the training, skills and confidence to make culturally appropriate spiritual care available to their patients.[129] In some cases, this results in avoiding advance care planning for people from certain religious groups.[130, 131] Overall, a lack of spiritual support is associated with worse quality of life and satisfaction with care, more aggressive treatment, increased costs and complicated grief, particularly among ethnic minority groups.[132, 133]

CASE STUDY 3. ETHICS AND RELIGION IN PALLIATIVE CARE

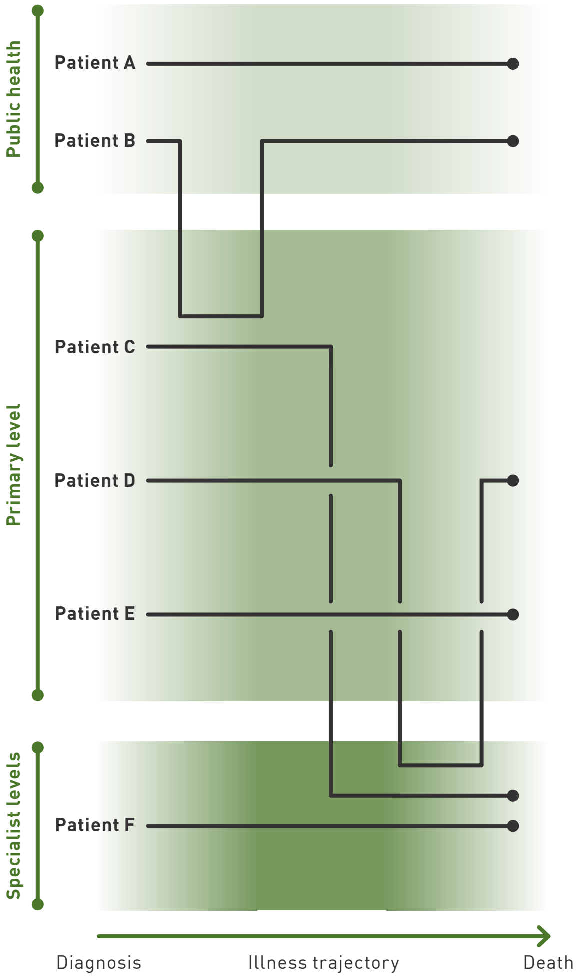
In 2018, the World Innovation Summit for Health (WISH) commissioned a survey through YouGov to gauge public sentiment on the integration of religious beliefs into palliative care. Most respondents from Indonesia, Malaysia, Oman and Qatar agreed that considering religious beliefs enhances care quality. The subsequent report, *Palliative Care and Islamic Ethics*, underscored critical gaps in Islamic ethical frameworks within palliative care policies across Muslim-majority countries. Key ethical concerns, such as decisions on life-sustaining treatments and euthanasia, were addressed with recommendations tailored to align with Islamic principles.[134] Building on these findings, WISH spearheaded the 2021 Doha Declaration on Palliative Care, a collaborative effort involving Qatar's Ministry of Public Health, Hamad Medical Corporation, and other global health organizations, including the Worldwide Hospice Palliative Care Alliance, SANAD, the Home Hospice Organization of Lebanon and Alzheimer's Disease International. Emphasizing religiously informed palliative care counseling and ethical guidelines, the declaration serves as a catalyst for policy reform and international co-operation in advancing culturally sensitive end-of-life care solutions.[135]

INCORPORATING EVIDENCE-BASED BEST PRACTICE

To address the growing demand and to correct the lack of progress on the WHA Resolution 67.19 recommendations, it is crucial to use evidence for palliative care interventions, models and delivery. Transferable and implementable evidence for models, quality and costs is the foundation for expanding equitable access to effective services.

EVIDENCE FOR MODELS OF CARE

A substantial evidence base shows that integrating palliative care in the patient's preferred setting improves outcomes.[136] Even so, this evidence base has largely been generated in high-income settings.[137] The various settings where patients receive care can be seen in the figure below.[138] Access may depend on location, diagnosis, disease and symptom severity, service availability, extent of family support, and socioeconomic position.



Some people with life-limiting illness can have their palliative care needs met through public health services and community support, such as peer support groups, social networks, and freely available educational offerings. Others might need referrals to more intensive services through channels like community helplines.

Most people prefer to die at home. All palliative care services help elicit people's goals of care so they can live and die according to their wishes.

Most people require only primary level palliative care or palliative care services integrated into the care they receive from other specialties, like their oncologist or their cardiologist. This might include care provided in a primary care clinic or in the person's home.

Some people with complex needs require specialist palliative care services throughout their disease course. Others need intensive support managing symptoms only when complex needs arise or near the end of life.

In most instances, palliative care is provided on a spectrum depending on patient complexity and available resources. Often, models (see page 21) do not operate in a vacuum, but rather as interrelated and complementary services with referral pathways which patients navigate between as their needs change.[139] Each model offers some benefits for certain populations of people who require palliative care, but also comes with specific challenges. For example, specialist palliative care offers the most comprehensive and intensive model, but requires significant time, human and physical resources and often is not available in low-resource settings.[140] As such, it should be reserved for those with the most complex needs, such as severe or difficult to manage symptoms, complex social needs, or complicated family dynamics.[141] Palliative care integrated into primary and community care offers the best opportunity to meet UHC goals in a sustainable and equitable way, but can have inconsistent quality and accessibility due to variations in resource availability, generalist healthcare provider training, primary care infrastructures, and funding mechanisms.[142, 143] It is more widely available in most places, but may not provide sufficient support for people with complex needs.

Palliative care integrated into primary and community care offers the best opportunity to meet UHC goals in a sustainable and equitable way, but can have inconsistent quality and accessibility.

In 2018, the Lancet Commission on Palliative Care and Pain Relief published their low-cost Essential Package of Palliative Care that has the potential to alleviate most serious health-related suffering around the world.[144] Costed at just $2.16 per capita per year in low-income countries, this package includes a list of essential medicines (including morphine), basic medical equipment and essential services that can be provided by specialists, generalists or community health workers with appropriate training. A similar package for pediatric palliative care has also been identified based on the Lancet Commission report.[145]

Evidence supporting models of palliative care (PC)

Model of care	Description	Evidence for effectiveness	Strengths	Limitations	Gaps in evidence
PC integrated into primary care	Integrated, continuous and comprehensive PC services in a primary care setting delivered to people throughout the life course.[146]	Randomized controlled trials (RCTs) for people with many diagnoses have shown that primary PC improves quality of life (QoL), some symptoms and likelihood of dying at home.[147–149]	• Expanding access through primary care is the most economical and equitable means to achieve universal health coverage (UHC)[150,151] • More widely available and easily accessible than specialist services[152]	• Largely limited to basic or core PC services	Most evidence comes from high-income countries and focuses on multidisciplinary generalists in primary care clinics and in homes.[153] Models in low- and middle-income countries (LMICs) can look different, and many have not been evaluated.[154]
Integrated PC within another specialty	Blends disease- or condition-oriented care by specialists such as oncology, cardiology, geriatrics or pediatrics with PC throughout the disease course.	Integrated care can improve outcomes in a variety of diagnoses across age groups, and most national and international guidelines now call for early integration of PC for people with cancer,[155] heart failure,[156,157] HIV,[158,159] chronic obstructive pulmonary disease (COPD)[160] and dementia,[161,162] and for children with serious illness.[163–165]	• Maintains care continuity • Fosters holistic assessment and management of needs specific to a person's diagnosis	• Largely limited to basic or core PC services	Most evidence comes from oncology and nephrology.[166]
Specialist PC	The most intensive, comprehensive model of PC for people and families with complex needs.[167]	In-hospital and outpatient, specialist PC has been shown to improve health-related QoL, physical symptom burden, depressive symptoms, satisfaction with care, and chances of dying at home.[168–171] In the community, it improves symptom burden and QoL and reduces healthcare use.[172–174] Specialized hospice care has been shown to reduce emergency department visits, hospital admissions, length of stay, healthcare costs and invasive interventions, and improve pain and symptom management, satisfaction with care, and the likelihood of dying at home.[175]	• Specialist PC teams provide clinical services and health system leadership, supporting generalists in referrals, research and capacity building, particularly in LMICs.[176–178] • Training and mentorship from experienced specialists improve generalists' knowledge, skills and confidence in delivering basic PC services.[179,180]	• Workforce shortages of specialists • Specialist PC costs more than other models such as primary PC	Most evidence comes from high-income countries, and even among those, few focus on the needs of children or minority ethnic groups.[181] The impact of hospice care for people with non-cancer conditions is not well documented but trends toward improvements in QoL, satisfaction with care, and rehospitalizations.[182,183]

Model of care	Description	Evidence for effectiveness	Strengths	Limitations	Gaps in evidence
Public health PC	An approach to PC where health promotion and community support and action are the main focus.[184]	Recent reviews found that literature on public health-oriented PC interventions is growing and offers a sustainable solution to expanding reach and access, especially for people who have historically been marginalized by PC services.[185,186]	• Public health PC harnesses community strength to improve the experience of living with life-limiting illness, dying and bereavement.[187–190] • This model merged organically out of necessity and strong community networks in LMICs.[191]	• Newly described in scientific literature	Though it began and is largely concentrated in LMICs, most published evidence on the subject comes from high-income settings.[192]
Pediatric PC	A specialized subset of PC intended to holistically care for children and young people's (CYP's) body, mind and spirit from diagnosis of a life-limiting condition, regardless of treatment status, and to support their family members.[193]	For those with cancer, pediatric PC is associated with increased advance care planning, less invasive interventions at the end of life, and a lower likelihood of dying in hospital.[194,195] For those with any diagnosis, pediatric PC is associated with improved QoL, better caregiver outcomes,[196] decreased symptom burden, and increased likelihood of dying at home.[197] Research has been increasing in recent years, particularly in LMICs.[198]	• The number of CYP surviving and living longer with life-limiting illness and pediatric PC need is increasing rapidly.[199] • Pediatric PC offers CYP with life-limiting illness and survivors symptom management and holistic support that is distinct from that offered to adults.[200]	• There are challenges around when and how to transition to adult care.[201]	Similarly to adult PC, pediatric PC research and service availability is concentrated in high-income countries.[202]
Nurse-led PC	PC model in which nurses (general or advanced practice) lead or co-ordinate services.	Nurse-led models of PC have been shown to improve QoL, symptom experience, psychosocial wellbeing, and advance directive use for people with cancer,[203] HIV,[204] COPD[205] and heart failure.[206] Nurse specialist-led PC services reduce costs.[207] In LMICs, nurse-led PC models, including link nurses,[208] have been shown to improve QoL and activities of daily life.[209]	• With nearly 30 million active practitioners and 59% of the global healthcare workforce, nurses are involved in 90% of patients' interactions with healthcare systems.[210] • In LMICs in particular, nurses often serve as critical frontline, and often only providers of PC.[211]	• In many countries, regulatory constraints and scope of practice disputes limit nurses' autonomy, particularly in prescribing.[212–215]	The quality of nurse-led care compared with other models (ie, physician-led care) is less well described in the scientific literature.[216]

Model of care	Description	Evidence for effectiveness	Strengths	Limitations	Gaps in evidence
Palliative rehabilitation	Palliative rehabilitation empowers people with life-limiting illness to maintain optimal function, autonomy, and sense of control with a focus on person-centered goals for improving quality of life.[217]	Rehabilitation in PC has been proven to improve symptoms, activities of daily life, and QoL for those with cancer,[218] COPD,[219] heart failure[220] and neuromuscular disease.[221]	• In 2023, WHO released a policy brief strongly advocating for the integration of rehabilitation in PC services to promote resilience, independence, and improved function.[222]	• The palliative rehabilitation workforce is very limited, especially in LMICs.[223]	More research is needed to determine the models, timing and dosage that optimizes outcomes.[224]
Bereavement support	Bereavement care encompasses pre-death education and symptom management, psychosocial and spiritual support integrated throughout the dying experience, and resilience and legacy building post-death.[225]	Psychological grief interventions,[226] support groups,[227] community-based support programs,[228] web-based psychotherapy, and integrated support with PC services[229] improve bereavement outcomes for some, often with longer exposure leading to better, more sustainable improvement.	• Includes a spectrum of support services, from basic education and psychosocial support to intensive cognitive behavioral therapy, depending on the person's needs.[230]	• Timing, extent and nature of people's needs vary widely so it is difficult to develop a multipurpose approach.[231]	Reviews of bereavement support often cite small sample sizes and poor methodological rigor as limitations to making definitive statements about effectiveness of interventions.
PC in emergencies, natural disasters and humanitarian crises	PC in emergencies addresses holistic concerns through context-specific symptom management and targeted mitigation of suffering wherever possible.[232,233]	Including PC in emergency responses helps to appropriately prioritize scarce resources, conduct sensitive communications, engage volunteers in providing psychosocial and bereavement care and boost staff morale.[234]	• Climate change and political instability are expected to increase PC demand due to increased respiratory and waterborne illnesses, more frequent extreme weather and forced mass migration, so it is essential to update emergency guidelines to include essential PC.[235]	• In crisis settings, PC is often overlooked in favor of life-saving measures[236]	Few models of PC have been systematically evaluated in emergency settings.[237]

CASE STUDY 4. EXPANDING ACCESS TO HIGH-QUALITY PRIMARY PALLIATIVE CARE THROUGH PROJECT ECHO

Training and mentoring primary care providers to deliver basic palliative care services remains a challenge to expanding access to palliative care.[238] Project ECHO (Extension for Community Healthcare Outcomes) was originally developed by a team at the University of New Mexico to improve access and quality of care for people with hepatitis C. The project has been adapted to support primary care providers in rural and underserved areas to deliver palliative care. Project ECHO supports physicians, nurses, community health workers, social workers, physiotherapists and volunteers through regular (weekly to monthly) online teaching and case discussions with specialists at a central hub.[239] It has been proven to be acceptable, sustainable, and effective in improving primary care providers' knowledge, skills and confidence in delivering palliative care to their patients,[240] particularly in LMICs.[241–245] Since 2003, Project ECHO has delivered collaborative training and educational sessions on a variety of health and social care topics to nearly 6 million participants in 209 countries.[246]

CASE STUDY 5. PALLIATIVE CARE INNOVATIONS DURING THE COVID-19 PANDEMIC

Across the globe, the COVID-19 pandemic threatened to overwhelm palliative care services and forced health systems to adapt to rapid shifts in disease burden, emerging evidence, and workforce and equipment shortages.[247]
The pandemic strengthened collaboration between palliative care specialists and non-specialists[248] and forced change that had been resisted previously, including:

- Telehealth outreach and virtual working[249, 250]
- Streamlined referral pathways with a central co-ordinator to triage and manage the allocation of new patients and those with changing needs[251]
- Redeployment of retired or inactive healthcare workers[252]
- Focus on staff wellbeing and prevention of burnout.[253]

A 2024 survey of palliative care professionals found that 97 percent continue to use technology (telehealth conferencing, family meetings on Zoom and virtual education sessions) more than they did pre-pandemic.[254] The response to the pandemic highlighted vulnerabilities in the global healthcare system,[255] but also the ingenuity of healthcare systems in improvising, evaluating and refining solutions to seemingly impossible problems. It also underscored the need to include palliative care in future pandemic preparedness.[256]

CARE QUALITY AND OUTCOMES

Integral to the development and evaluation of palliative services is measurement of person-centered and clinically meaningful outcomes. Tools to assess the performance of palliative care delivery in appropriate domains (physical and psychological symptoms, emotional and spiritual needs, carer support) need to be accurately defined and validated to ensure that the intended indicators are being measured.[257] With more than 500 different measures available to assess outcomes in palliative care from the perspective of patients of different ages and developmental stages, family members, staff members and the healthcare system,[258] it can be difficult to identify the best tool for a specific purpose. Measures developed and validated specifically for people with life-limiting conditions commonly used in research and clinical practice include:

- Palliative outcome scale (POS) family of measures (including the Integrated Palliative Outcome Scale (IPOS),[259] the African Palliative Care Association POS,[260] IPOS-Renal,[261] and IPOS-Dementia)[262]
- Edmonton Symptom Assessment System[263]
- Memorial Symptom Assessment Scale[264]
- Support Team Assessment Schedule[265]
- Core Quality of Life Questionnaire.[266]

These tools are currently used in routine clinical practice and research to conduct assessment, inform care planning, monitor response, conduct audit, and inform policy and service management.[267,268]

CASE STUDY 6. THE CHILDREN’S PALLIATIVE CARE OUTCOME SCALE (C-POS)

Outcome measurement for children and young people with life-limiting conditions can present additional challenges: children often have different care priorities to adults, varying developmental stages, and ability to self-report. They also bring additional considerations for parents and siblings.[269] Researchers in Uganda, Kenya and South Africa elicited from and defined meaningful outcomes for children and young people with life-limiting illness and their families, to develop an initial children’s outcome scale.[270] This work led to the validation and refinement of a person-centered outcome measure (C-POS) that captures core symptoms for this population[271] and prompted pediatric outcomes research in countries such as Belgium, Jordan, Turkey and the UK. Items in the tool include questions related to:

- Symptoms and concerns (can be answered by the child or by proxy):
  - Pain
  - Other symptoms
  - Having appropriate information
  - Being able to undertake usual activities
  - Worry
  - Being able to express feelings

  - Being able to do things you enjoy
  - Living life to the fullest
- Parent or caregiver items:
  - Getting enough sleep
  - Access to information about the child's condition
  - Support needed to care for the child
  - Impact of child's condition on family
  - Support to plan for future care.

More than 230 children, young people and parents have been involved in every stage of the outcome measure development, validation and dissemination, from identifying research priorities to writing and refining the questions.[272–275] The development of C-POS highlights how research in Sub-Saharan Africa has pioneered developments around the world.

ECONOMICS OF PALLIATIVE CARE

Managing life-limiting illness can lead to catastrophic financial impact for patients, families and health systems.[276,277] Economic evaluation of palliative care services can help decision-makers to finance interventions that bring the greatest benefit for available resources.

Decision context for policymakers and health system financers

In high-income countries, the 1 percent of people who die annually account for about 10 percent of all healthcare expenditure, and spending is concentrated in high-intensity treatment in the last days of life.[278–281] People with life-limiting illness often experience modifiable problems, including severe pain or depression. They are at risk of avoidable hospital admissions, and they receive care inconsistent with their preferences (including death not in their preferred place).[282–284] The cost of unpaid family care is often comparable to formal care in high-income countries.[285–287] In many countries people face additional personal expenses for hospital stays and medications, increasing the risk of catastrophic health expenditure.[288] Even so, there is widespread evidence that this spending yields poor value.[289]

In LMICs, the prevalence of poor-value care remains high, but the initiators of these outcomes are very different. While people in high-income countries experience death in an increasingly medicalized context, people in LMICs often lack access to care that is proven to be cost-effective, including opioids.[290] In the absence of UHC, people pay for a high proportion of care themselves,[291] but many patients lack sufficient knowledge and information to make good choices as palliative healthcare 'consumers'.[292,293] Reliance on out-of-pocket personal spending means that people with life-limiting illness and their families often have to choose between funding (often non-beneficial) treatment and paying for basic necessities.[294,295]

Economic evaluations to inform palliative care service development and improvement

A 2019 systematic review of economic evaluations in palliative care concluded that palliative care is cost-effective compared to standard practice.[296] Another review of palliative care services in LMICs found 10 studies, all of which reported cost savings, though not all studies constituted a full economic evaluation.[297] Given the extensive literature on economic evaluations in similar populations,[298–300] very little economic research has been conducted in the palliative care setting.

Alongside the evidence that palliative care improves outcomes, it represents better care and also reduces costs in the right circumstances.

Despite the lack of evaluations of palliative care cost-effectiveness, there is significant evidence indicating the positive economic impact of palliative care in acute and critical care,[301,302] for people with cancer,[303,304] and for those with life-limiting illness in all settings.[305,306] Evidence suggests that palliative care reduces costs by 5 to 20 percent, although the methodological quality of studies is highly variable. Reported savings appear to accrue through lower intensity of care (fewer tests, fewer hospital and Intensive Care Unit admissions) and better integrated care (early hospital discharge, contact with home care teams). Alongside the evidence that palliative care improves outcomes,[307–309] this implies that palliative care represents better care and also reduces costs in the right circumstances. However, it is largely unclear how much observed savings reflect costs shifting from health systems to households.[310,311]

CONCLUSION AND RECOMMENDATIONS FOR IMPLEMENTING ESSENTIAL PALLIATIVE CARE

CONCLUSIONS

Unless urgent, evidence-informed, co-ordinated action is taken, the individual, health system and health economic benefits of palliative care will not be achieved under UHC. Ten years after the 2014 WHA Resolution 67.19 on Palliative Care, palliative care provision remains patchy and unequal around the world, and most people cannot access basic palliative care.[312] Palliative care for children and adults is an essential health service within UHC, and the lack of coverage must be corrected to meet the United National Sustainable Development Goals and WHO priority objectives.[313]

The risk of maintaining the status quo and not significantly and purposively expanding access to palliative care equitably would represent a failure to respond to the enormous – and growing – level of preventable suffering over the next few decades.[314] The evidence to date is encouraging in showing improved policy and service provision in some areas for specific populations. However, despite the availability of valid person-centered outcome measures for this population, they have not been routinely applied in practice to ensure that *quality is maintained* as *coverage is expanded*.

International efforts to expand palliative care provision across all ages must be increased and strengthened to overcome identified challenges. Improved palliative care provision must be sustained to have a positive impact on dealing with future health-related suffering, particularly in LMICs, and for vulnerable populations. The integration of palliative care into primary care offers a promising avenue for extending access while maintaining quality. However, to be effective, efforts must be tailored to local contexts and cultural norms.[315]

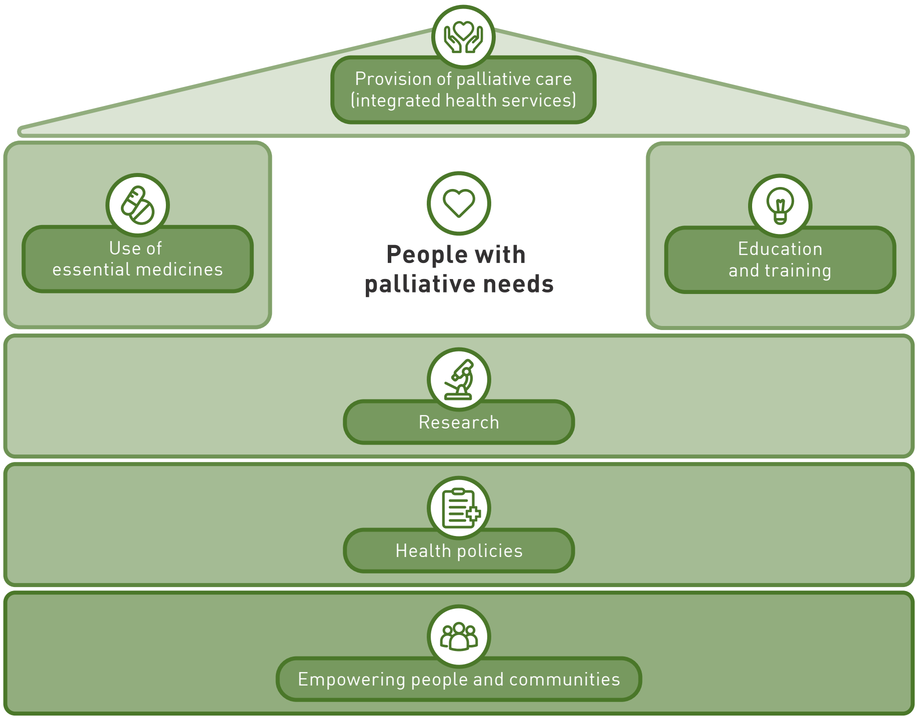
RECOMMENDATIONS

Collaborative efforts and targeted interventions in a range of identified priority action areas can strengthen the global delivery of and access to palliative care as an essential, effective, cost-effective service for all who need it.

Essential palliative care entails minimum basic services that should be available for people globally, regardless of how resource-constrained their setting is.[316] Based on increasing global need, inequity in access to services, and the depth of evidence supporting palliative care integration, targeted capacity building and policy transformation are crucial to meet the rapidly increasing need for palliative care.[317]

In 2021, WHO published a conceptual model (see figure below) of palliative care development that outlined its essential components and indicators for progress to ensure access to timely and effective palliative care for all children and adults.[318]

These components are: health policies; empowering people and communities; provision of palliative care through integrated health services; education and training; use of essential medicines; and research.



Source: WHO (2021)[319]

We have developed recommendations for each of these essential components that require immediate, co-ordinated action to improve progress on WHA Resolution 67.19 to provide more equitable palliative care.

Our recommendations are outlined below with guiding notes and are summarized on page 34.

Health policies

Health policies refer to political commitment and leadership to ensure that palliative care is operationalized in national, regional and local policies, standards and guidelines.[320] Translating identified needs into policies that outline implementable, cost-protected UHC packages at national, regional and local levels, with a focus on equity and stakeholder engagement, is crucial to turning research and service development into actionable change.[321] This means that palliative care services should be integrated into public healthcare systems with financing mechanisms to reduce catastrophic expenditures and out-of-pocket personal costs.

We propose the following to strengthen palliative care health policies:

Recommendation 1. Every country should have an evidence-based national palliative care policy that includes sustainable public funding for services. Whether this is a new policy or integrated into existing policy, this should include guidelines on education, delivery, integration into primary care, and public funding to support delivery of high-quality palliative care for people of all ages.

a. The WHO developed a UHC Service Package Delivery & Implementation (SPDI) tool to help local, regional and national teams build, implement and cost UHC packages.[322] These evidence-based, buildable packages, made up of combinations of elements from the UHC Compendium of Health Interventions, can be complex, comprehensive packages including everything a country needs to implement a national UHC package, or simple, domain-specific packages for an individual service to be delivered.

b. When public funding falls short, governments should capitalize on and facilitate alternative sources (non-governmental organizations (NGOs), civil society organizations) to bridge gaps.

Empowering people and communities

People and communities must be enabled to be active in their own healthcare decision-making, and also in palliative care research, service development, and implementation. Tailoring interventions by engaging communities in the development process, and incorporating cultural norms and preferences has improved access to and use of palliative care services and reduced stigma.[323–325] Though achieving high-level community participation and ownership is complex and difficult,[326] it is crucial to leverage community strengths and networks to support the delivery of palliative care by encouraging and facilitating healthcare institutions, community-based organizations, faith-based groups and other stakeholders to collaborate.

People and communities must be enabled to be active in their own healthcare decision-making, and also in palliative care research, service development and implementation.

We propose the following to encourage empowerment of people and communities:

Recommendation 2. Governments and healthcare workers should seek to improve the general public's understanding of palliative care and 'death literacy' (knowledge and understanding of end-of-life and death care options), including through public awareness campaigns, peer networks, inclusion in research and service development, and community engagement.[327]

Recommendation 3. Researchers and healthcare workers should empower and facilitate community action by reinforcing that stakeholder input is integral to ensuring that palliative care services meet the needs of their target population.

a. The WHO's framework for meaningful engagement of people living with non-communicable diseases defines and operationalizes the principles and enablers of meaningful community engagement.[328]

b. Methods for facilitating meaningful community engagement should be developed locally with a focus on cultural appropriateness.

Provision of palliative care through integrated health services

National health and social care capacity must meet the growing needs of adults and children with life-limiting illness equitably without compromising quality.[329,330] Strengthening palliative care and expanding access through primary and community care offers the best opportunity to meet UHC goals in a sustainable and equitable way.[331,332]

We propose the following to strengthen palliative care provision through integrated health services:

Recommendation 4. Governments should improve access to palliative care services equitably for people of all ages, paying particular attention to those in LMICs and vulnerable populations to correct and prevent inequities. The most effective and sustainable way to do this is by strengthening and integrating primary and community care services.[333,334]

- **a.** Governments should ensure palliative care services are integrated into implementable UHC packages that capitalize on strengths of local health systems, communities, civil society organizations and NGOs, and international agencies[335] and that palliative care services are context-specific and age and culturally appropriate.[336]

Recommendation 5. Governments and international organizations should establish mechanisms for ongoing monitoring and evaluation of palliative care service availability and quality on regional, national and/or local levels to identify gaps in service provision, barriers to access and areas for improvement.

- **a.** Steps to achieve this include: leveraging technology to collect real-time data and providing a platform for virtual collaboration between countries, regions and service providers.
- **b.** Develop a global reporting system where Member States are requested to submit data on palliative care initiatives, programs and outcomes.
- **c.** Conduct primary research on the development, delivery and outcomes of locally appropriate models of care in LMICs to redress the imbalance of evidence currently favoring high-income countries.

Recommendation 6. The WHO should report progress in each component of palliative care development every two years to track temporal changes since WHA Resolution 67.19.

- **a.** Document case studies of successful initiatives to provide insights into effective strategies and challenges faced.
- **b.** Develop a system for international dissemination of findings (publication, international conferences, workshops) to facilitate action.

Education and training

Palliative care provision for adults and children depends on adequately trained specialists, non-specialists, volunteers and caregivers with the knowledge and confidence to effectively deliver care.[337] Core and advanced education, training and mentorship for healthcare professionals, volunteers and caregivers must be available at all levels (undergraduate, postgraduate, continuing professional education).

We propose the following to strengthen palliative care education and training:

Recommendation 7. Universities and health systems should provide evidence-based, basic palliative care education and training for all non-specialist healthcare workers. This should be provided for healthcare professionals, volunteers and caregivers, and be multidisciplinary where possible to foster comprehensive care.

- **a.** Develop an evidence base of effective education and training curricula bolstered by positive long-term outcomes that can be shared across settings.
- **b.** Ensure that health professionals, community health workers and volunteers working to deliver palliative care services have access to evidence-based guidelines, protocols and referral processes.

Recommendation 8. Health systems should develop the specialist workforce in LMICs to be leaders in research and practice and to support non-specialists.

Use of essential medicines

All levels of the healthcare system must have access to essential palliative care medicines (non-opioids and non-steroidal anti-inflammatory medicines, opioid analgesics, and medicines for other common symptoms).[338] The benefit and cost-effectiveness of the WHO's Model List of Essential Medicines for Pain and Palliative Care is well documented for adults[339] and children,[340] yet legal, regulatory, structural and cultural barriers prevent millions of people, primarily in LMICs, from accessing pain and symptom relief.[341,342]

We propose the following to facilitate the use of essential medicines globally:

Recommendation 9. Governments, health systems and healthcare workers should acknowledge the transformational benefit of low-cost, effective opioids for those with health-related suffering.[343]

Recommendation 10. Governments should ensure that all essential medicines are available for those who need them. Steps to achieve this include:

- **a.** Collaborating with regulatory bodies to streamline the approval and supply chain processes for essential medicines;
- **b.** Engaging in policy advocacy to address legal and regulatory barriers that may impede access to essential palliative care medicines for people in any setting, including at home, while ensuring safe use;

c. And including capacity building in sectors other than health, such as industry and law enforcement, for multisectoral stakeholder dialogs that highlight the importance of oral opioids for pain management, and agree actionable strategic plans.[344]

Recommendation 11. Governments and researchers should track palliative care medication use, patterns, coverage and needs to inform policy decisions and supply planning.

Research

Rigorous palliative care research informed by key stakeholders (people with life-limiting illness, caregivers, communities, health workers, policymakers) is crucial to meeting the growing need.[345,346] Historically, research funding for palliative care is abysmally low,[347] and most has been concentrated in high-income countries, conducted by physicians, in cancer conditions, and for adults.[348,349] Expanding research capacity in LMICs – led by disciplines including social scientists, health economists, nurses, and allied health professionals, and for non-cancer conditions, children, and other vulnerable groups – is crucial to building context-specific palliative care services.[350–352] While building research capacity is not the end goal, it is the first step in developing and testing models of care and implementation approaches that are effective, acceptable, sustainable and transferable, and that efficiently use scarce resources to meet growing palliative care need.[353]

We propose the following to strengthen palliative care research capacity:

Recommendation 12. Researchers should focus on developing and adapting models of palliative care specific to the unique cultural, situational and socioeconomic context of LMICs and historically underserved populations.

a. International collaborations should be encouraged to enhance research by pooling diverse insights and resources, leading to more robust models of care.

b. Findings from research should be actively and freely shared through various global platforms (conferences, academic journals, policy briefs, community engagement) to influence practice and inform policy.

c. Universities and health systems should develop and sustain research groups dedicated to palliative care.

Recommendation 13. Governments and universities should support capacity building for research, applying input from patients, families and communities wherever possible to ensure that service development fits the needs of the people they target.

Recommendation 14. Researchers should use validated person-centered and clinically relevant outcome measures to develop, evaluate, audit, cost and improve services.

a. This should include thorough economic evaluations of services so that costs to governments and patients and their families are known.

Use of essential medicines

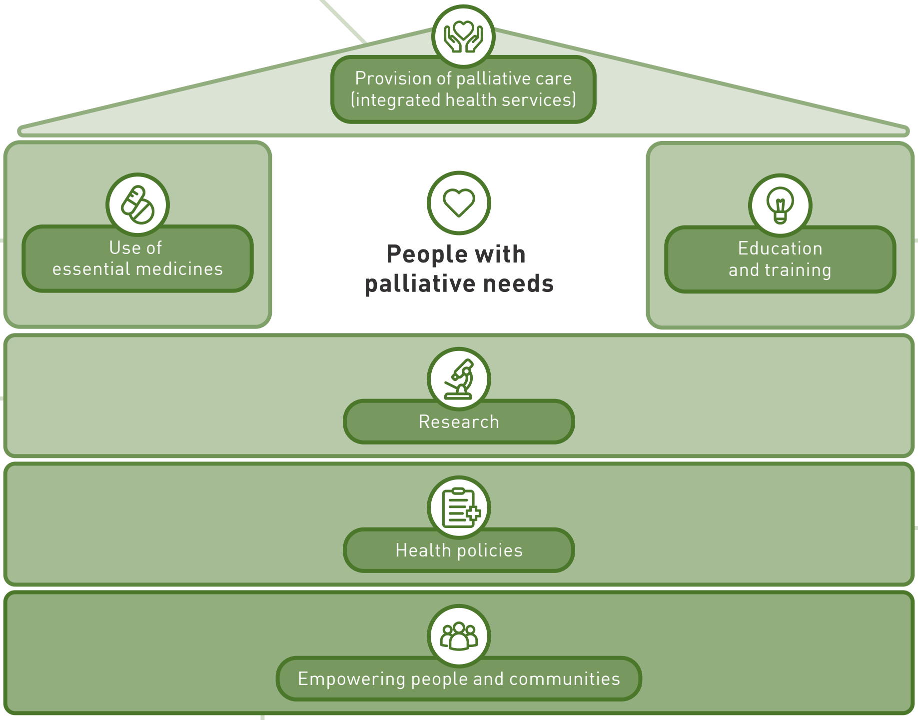
- Acknowledge the transformational benefit of low-cost, effective opioids for those with serious health-related suffering.
- Ensure that countries have all the palliative care medicines on the essential medicines list for both adults and children.
- Conduct research to gather data on medication usage, patterns and needs to inform policy decisions and supply planning.

Provision of palliative care

- Improve access to palliative care services equitably for people of all ages, paying particular attention to LMICs and vulnerable populations to correct and prevent inequities.
- Establish mechanism for ongoing monitoring and evaluation of palliative care service availability and quality on regional, national, local levels to identify gaps in service provision, barriers to access and areas for improvement.
- Report progress in each component of palliative care development every two years to track temporal changes since WHA Resolution 67.19.

Education and training

- Provide evidence-based, multidisciplinary education and training on the basics of palliative care and use of essential medicines for specialists, non-specialists, volunteers and caregivers alongside mentorship from experienced professionals.
- Develop specialist workforce in LMICs to be leaders in research and practice and to support non-specialists in providing palliative care.



Research

- Focus research on adapting successful models of palliative care to fit the unique cultural, situational and socioeconomic context of LMICs and historically underserved populations.
- Support capacity building for research applying input from patients, families and communities wherever possible to ensure service development fits the needs of people they target.
- Utilize validated person-centered and clinically relevant outcome measures to develop, evaluate, audit, cost and improve services.

Empower people and communities

- Improve the general public's death literacy and understanding of palliative care.
- Empower and facilitate community action by reinforcing that stakeholder input is integral to ensuring that palliative care services meet the needs of their target population.

Health policies

- Ensure every country has evidence-based national palliative care policies to support the people's right to receive high-quality palliative care.
- Call for public funding for palliative care so costs are not financed out-of-pocket.
- Establish resource-sharing agreements to pool funding, expertise and other resources for more effective service delivery.

Source: WHO (2021)[354]

ABBREVIATIONS

C-POS	Children's Palliative care Outcome Scale
CNS	central nervous system
COPD	chronic obstructive pulmonary disease
CYP	children and young people
IPOS	Integrated Palliative Outcome Scale
LMICs	low- and middle-income countries
MOOCs	Massive Open Online Courses
PC	palliative care
POS	palliative outcome scale
QoL	quality of life
RCTs	randomized controlled trials
SPDI	Service Package Delivery & Implementation
UHC	universal health coverage
WHA	World Health Assembly
WHO	World Health Organization

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This paper was written by Richard Harding and Asmus Hammerich in collaboration with:

- **Anna Peeler**, Cicely Saunders Institute of Palliative Care, Policy & Rehabilitation, King's College London
- **Oladayo Afolabi**, Cicely Saunders Institute of Palliative Care, Policy & Rehabilitation, King's College London
- **Katherine Sleeman**, Cicely Saunders Institute of Palliative Care, Policy & Rehabilitation, King's College London
- **Didi Thompson**, World Innovation Summit for Health
- **Maha El Akoum**, World Innovation Summit for Health
- **Nahla Gafer**, Consultant, WHO EMRO

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- **Hanadi Al Hamad**, National Lead – Healthy Ageing, Qatar Ministry of Public Health
- **Julia Downing**, Chief Executive, International Children's Palliative Care Network
- **Julie Ling**, CEO, European Association for Palliative Care and Consultant, World Health Organization European Regional Office
- **Laura Dale-Harris**, Executive Director, Global Treehouse Foundation
- **Lubna Izziddin**, Founder and President, SANAD, The Home Hospice Organization of Lebanon
- **Manal Abdul Majeed Hussain Al-Zadjali**, Dean, Higher Institute of Health Specialties and Secretary General, Oman Cancer Association

- **Maryam Rassouli**, Director General – Nursing Services, Iranian Ministry of Health and Medical Education
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- **William E Rosa**, Assistant Attending Behavioral Scientist, Memorial Sloan Kettering Cancer Center

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- **Anna Ray**, Consultant, WHO Headquarters
- **Bente Mikkelsen**, Director, Noncommunicable Diseases, WHO Headquarters
- **Giuseppe Troisi**, Technical Officer, Noncommunicable Disease Prevention, WHO EMRO
- **John Fogarty**, Lead for primary care services, Integrated Health Services, WHO Headquarters
- **Lamia Mahmoud**, Regional Advisor for Noncommunicable Disease Prevention, WHO EMRO
- **Megan Doherty**, Palliative Care Consultant, WHO Headquarters
- **Roberta Ortiz**, Global Initiative for Childhood Cancer, Medical Officer, WHO Headquarters
- **Rudi Eggers**, Director, Integrated Health Services, WHO Headquarters
- **Teri Reynolds**, Clinical Services and Systems Unit, Integrated Health Services, WHO Headquarters

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APPENDIX. WORLD HEALTH ASSEMBLY (WHA) RESOLUTION 67.19 ON PALLIATIVE CARE

WHA Resolution action item	Progress since 2014
For Member States	
1. To develop, strengthen and implement, where appropriate, palliative care policies to support the comprehensive strengthening of health systems to integrate evidence-based, cost-effective and equitable palliative care services in the continuum of care, across all levels, with emphasis on primary care, community and home-based care, and universal coverage schemes.	• In 2019, 50% of countries reported having palliative care within an operational national noncommunicable diseases policy or strategy.[355] • Between 2005 and 2019, 82% of countries in Europe increased their number of specialist palliative care services. High-income countries showed significant increases in the number of home care teams, inpatient services, and hospital support teams, while low- and middle-income countries (LMICs) only showed significant increases in inpatient services.[356] • In the same time period in Latin America, the number of palliative care teams increased, but most services were offered outpatient, and there were very few inpatient beds added.[357] • By 2019, 19 of 51 (37.3%) surveyed European countries had set standards for pediatric palliative care, 22 (43.1%) had a national association, and 14 (27.5%) offered education for either pediatric doctors or nurses.[358] • A 2020 review of palliative care policy development found that 55 countries (28%) had any national policy plan for palliative care.[359] • The *Tracking Universal Health Coverage: 2023 Global Monitoring Report* did not include any specific palliative care indicators.[360] • Regional atlases of palliative care show that there is still a great need for the development of children's palliative care globally, and that its development lags significantly behind that for adults.[361–364] • World Health Organization (WHO) developed an Essential Package of Palliative Care for Primary Health Care that represents the minimum services, medicines and human resources that should be available in district or community primary care clinics around the world.[365] • European Association for Palliative Care Reference Group in Primary Care produced a toolkit to help countries implement palliative care in the community. It includes policy, education, medication availability, and best practices including policy, education, essential medicines and implementation.[366]
2. To ensure adequate domestic funding and allocation of human resources, as appropriate, for palliative care initiatives, including development and implementation of palliative care policies, education and training, and quality improvement initiatives, and supporting the availability and appropriate use of essential medicines, including controlled medicines for symptom management.	• A 2017 estimate of palliative care workforce requirements suggests that only 400,000 healthcare workers deliver palliative care globally, falling short of the estimated 2 million needed.[367] • In 2021, 69% of countries reported funding for palliative care, representing little change from the last report in 2019.[368] • WHO's Global Survey on the Inclusion of Cancer Care in Health-benefit Packages 2020–2021 found that only 28% of countries surveyed had public sector packages that included palliative care services. These were mainly in upper-middle and high-income countries.[369]
3. To provide basic support, including through multisectoral partnerships, to families, community volunteers and other individuals acting as caregivers, under the supervision of trained professionals, as appropriate.	• In 2017, global estimates suggest that more than 1.2 million people volunteer in palliative care around the world.[370]

WHA Resolution action item	Progress since 2014
4. To aim to include palliative care as an integral component of the ongoing education and training offered to care providers, in accordance with their roles and responsibilities, according to the following principles: Basic training and continuing education on palliative care should be integrated as a routine element of all undergraduate medical and nursing professional education, and as part of in-service training of caregivers at the primary care level, including healthcare workers, caregivers addressing patients' spiritual needs, and social workers. Intermediate training should be offered to all healthcare workers who routinely work with patients with life-threatening illnesses, including those working in oncology, infectious diseases, pediatrics, geriatrics and internal medicine. Specialist palliative care training should be available to prepare healthcare professionals who will manage integrated care for patients with more than routine symptom management needs.	• A 2020 review of palliative care education in undergraduate and graduate nursing programs in Europe found that 56% of surveyed countries did not identify palliative care as a mandatory subject.[371] • In 2020, no countries in Latin America had palliative care as a mandatory subject in nursing or medical schools.[372] • A 2021 report found that only eight countries in Latin America recognized palliative medicine as a medical specialty.[373] • A 2023 report from WHO South-East Asia Region showed that 40% of reporting countries had any palliative care included in medical or nursing curricula, and that 30% had any palliative care certificate, diploma or degree programs for health professionals.[374] • A 2023 global review of education programs on children's palliative care identified 114 programs, 75% of which were generalist level and 25% were specialist level. By WHO region, 31% came from Europe, 26% from the Americas, 16% from Africa, 16% from the Western Pacific, 10% from Southeast Asia and just 1% from the Eastern Mediterranean.[375]
5. To assess domestic palliative care needs, including pain management medication requirements, and promote collaborative action to ensure adequate supply of essential medicines in palliative care, avoiding shortages.	• Several global and regional Atlases of Palliative Care that describe palliative care need, provision and development indicators at a country level have been published since 2014.[376–380] • The Lancet Commission on Palliative Care and Pain Relief developed and released methodology to measure and predict serious health-related suffering in 2018,[381] which was updated in 2024.[382] • In 2021, WHO released a set of actionable indictors to assist countries in assessing palliative care development and gaps in service provision.[383] • In 2022, World Health Organization Regional Office for the Eastern Mediterranean (WHO EMRO) and the palliative care experts network for the region developed region-specific macro-indicators to track the progress of national palliative care programs in the Eastern Mediterranean.[384]
6. To review and, where appropriate, revise national and local legislation and policies for controlled medicines, with reference to WHO policy guidance, on improving access to and rational use of pain management medicines, in line with the United Nations international drug control conventions.	• A 2023 International Narcotics Control Board report showed that 19.8% of the global population consumed 86.1% of the globally produced morphine, highlighting the extreme, persistent global inequity of opioid access.[385] • The 2023 WHO report *Left behind in Pain* highlights persistent regional barriers to safe and timely access to morphine for medical use for adults and children, including national policies overly focused on preventing illicit use, restrictive administrative requirements for prescribing or dispensing morphine, and unpredictable and insufficient financial and human resources.[386]
7. To update, as appropriate, national essential medicines lists in the light of the recent addition of sections on pain and palliative care medicines to the WHO Model List of Essential Medicines and the WHO Model List of Essential Medicines for Children.	• A 2022 comparison of WHO's Model List of Essential Medicines and 137 country level lists found that there were substantial gaps in adopting WHO's official guidance.[387] • A related report found that country-level lists included significantly more opioids that the WHO list.[388] • A 2023 WHO South East Asia Region (SEAR) publication showed that just one out of 10 reporting countries had included oral opioids in their list of essential medicines.[389]

WHA Resolution action item	Progress since 2014
8. To foster partnerships between governments and civil society, including patients' organizations, to support, as appropriate, the provision of services for patients requiring palliative care.	• In 2021, WHO formed a palliative care working group comprised of experts from clinical practice, academia, government, non-governmental organizations, and patient advocates to foster cross-sectoral partnerships, form international networks and collaborate to progress the mission of the WHA Resolution. • A 2021 review of collaborative partnerships between governments and civil society organizations found that civil society's role in policy progress at global and national levels has been significant, with advocacy leading to collaborations in policymaking, service development and education.[390]
9. To implement and monitor palliative care actions included in WHO's Global Action Plan for the Prevention and Control of Noncommunicable Diseases 2013–2030.	• WHO reports on multinational capacity for the prevention and control of non-communicable diseases have been published in 2018,[391] 2020[392] and 2023,[393] all of which include palliative care development indicators.
For the WHO Director General	
10. To ensure that palliative care is an integral component of all relevant global disease control and health system plans, including those relating to non-communicable diseases and universal health coverage, as well as being included in country and regional co-operation plans.	• In 2017, the definition of universal health coverage (UHC) was updated to include palliative care in the continuum of essential health services.[394] • In 2021, the consolidated guidelines for HIV prevention, testing, treatment, service delivery and monitoring included palliative care.[395] • The *Tracking Universal Health Coverage: 2023 Global Monitoring Report* did not include any specific palliative care indicators.[396]

11. To update or develop, as appropriate, evidence-based guidelines and tools on palliation, including pain management options, in adults and children, including the development of WHO guidelines for the pharmacological treatment of pain, and ensure their adequate dissemination.	• Multiple WHO guidelines have been developed and updated for various aspects of palliative care delivery, including:
	  • Planning and implementing services for program managers[397]
	  • Pharmacological and radiotherapeutic management of cancer pain in adults and adolescents[398]
	  • Improving palliative care service quality[399]
	  • Integrating rehabilitation into palliative care services.[400]

12. To develop and strengthen, where appropriate, evidence-based guidelines on the integration of palliative care into national health systems, across disease groups and levels of care, that adequately address ethical issues related to the provision of comprehensive palliative care, such as equitable access, person-centered and respectful care, and community involvement, and to inform education in pain and symptom management and psychosocial support.	• Multiple WHO guidelines have been developed to help ethically integrate palliative care into national health systems, including:
	  • Integrating palliative care and symptom relief into primary care[401]
	  • Integrating palliative care in the response to humanitarian crises[402]
	  • Launched in 2024, WHO developed the UHC Service Package Delivery & Implementation (SPDI) tool to help local, regional and national teams build, implement and cost UHC packages.[403]

13. To continue, through WHO's Access to Controlled Medicines program, to support Member States in reviewing and improving national legislation and policies with the objective of ensuring balance between the prevention of misuse, diversion and trafficking of controlled substances and appropriate access to controlled medicines, in line with the United Nations international drug control conventions.	• In 2019, WHO's *Ensuring balance in national policies on controlled substances* and *WHO guidelines on the pharmacological treatment of persisting pain in children with medical illnesses* were discontinued based on concerns for conflicts of interest.[404] • Revised guidelines for managing pain in children were published in 2020.[405] • New adult guidelines are due for publication in December 2024.

WHA Resolution action item	Progress since 2014
14. 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.	• A 2021 report found that global opioid consumption declined from 216.3 to 151.5 morphine milligram equivalents per 1,000 inhabitants per day between 2009 and 2019.[406] • A 2022 International Narcotics Control Board report found that 9.9% of the morphine available globally was directly consumed, an increase from the previous decade.[407] • The amount of opioid analgesics consumed in South America tripled between 2002 and 2021.[408] • As of 2024, WHO's non-communicable diseases emergency health kits do not include medicines for pain and symptom management due to regulatory concerns.[409]
15. To work with the International Narcotics Control Board, the United Nations Office on Drugs and Crime, health ministries and other relevant authorities in order to promote the availability and balanced control of controlled medicines for pain and symptom management.	• According to International Narcotics Control Board data, global morphine consumption decreased from 6.1671 in 2014 to 4.4768 mg/capita in 2021.[410] • Global consumption of all opioids (excluding methadone) decreased from 43.05 mg/capita in 2014 to 28.559 mg/capita in 2021.[411]
16. To further co-operate with the International Narcotics Control Board to support Member States in establishing accurate estimates in order to enable the availability of medicines for pain relief and palliative care, including through better implementation of the guidance on estimating requirements for substances under international control.	• International Narcotics Control Board publishes yearly technical reports on global narcotic drug requirements, most recently in May 2024 using data from 2022.[412]
17. To collaborate with UNICEF and other relevant partners in the promotion and implementation of palliative care for children.	• In 2023, WHO and UNICEF collaborated to create the *Operational Framework for Primary Health Care: Transforming vision into action* which highlights the urgent need to integrate palliative care into primary care, and establish robust monitoring and evaluation frameworks.[413]

18. To monitor the global situation of palliative care, evaluating the progress made in different initiatives and programs in collaboration with Member States and international partners.	• In collaboration with the Worldwide Hospice Palliative Alliance, WHO published two Global Atlases of Palliative care, one in 2014,[414] and one in 2020.[415]
	• A WHO global survey from 2021 found:
	  • 43% of countries reported general palliative care availability (reaching at least 50% of patients in need) in a community- or home-based care setting, and 42% reported general availability in the primary care setting[416]
	  • Services were much more likely to exist in high-income countries compared to LMICs.[417]

19. To work with Member States to encourage adequate funding and improved co-operation for palliative care programs and research initiatives, in particular in resource-poor countries, in line with the program budget 2014–2015, which addresses palliative care.	• There are 14 professional journals with a focus on palliative care.[418] • By 2020, 141 of the 195 countries had published at least one palliative care paper, leaving 27.7% of countries (primarily LMICs) that have never published any palliative care related research.[419] • A 2022 bibliometric analysis of published palliative care research found that minimal international co-operation occured across countries.[420] • In the US and UK, palliative care research studies receive just 0.2% and 0.3% of all research funding, respectively.[421] • There has been a significant increase in research and publications on children's palliative care in the past 10 years, including an increase in countries publishing research with the Cancer and Palliative Care Outcomes Centre.[422]
20. To encourage research on models of palliative care that are effective in low- and middle-income countries, taking into consideration good practices.	• Between 2000 and 2020, India and China were the only LMICs in the top 15 most productive countries in palliative care research.[423]
21. To report back to the Sixty-ninth World Health Assembly in 2016 on progress in the implementation of this resolution.	• In 2016, a brief report was published by the WHO Secretariat outlining some aspects of global palliative care progress since the WHA Resolution.[424]

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