



Global Atlas of Palliative Care

2nd Edition



Acknowledgements and Authorship

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The views expressed in this publication do not necessarily represent the decisions, policy or views of the World Health Organization

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Acronyms

This list is confined to acronyms used more than once, and in more than one place, within the main chapters of this book.

AFRO	African Region of the World Health Organization
AMRO	Regional Office for the Americas of the World Health Organization
CESCR	Committee on Economic, Social and Cultural Rights
DR-TB	Drug Resistant Tuberculosis
EMRO	Eastern Mediterranean Region of the World Health Organization
EURO	European Region of the World Health Organization
ICESCR	International Covenant on Economic, Social and Cultural Rights
INCB	International Narcotics Control Board
INESCR	UN Committee on Economic, Social, and Cultural Rights
IOELC	International Observatory on End-of-Life Care
NHPCO	National Hospice and Palliative Care Organization
NCD	Non-communicable disease
PC	Palliative Care
SEARO	Southeast Asian Region of the World Health Organization
SHS	Serious Health-related Suffering
UHC	Universal Health Coverage
UN	United Nations
UNICEF	United Nations Children's Fund
WHO	World Health Organization
WHPCA	Worldwide Hospice Palliative Care Alliance
WPRO	Western Pacific Region of the World Health Organization

Foreword

Some say that palliative care is the best kept secret in healthcare. Today there are still far too many people that are unable to access this essential service, especially in low and middle-income countries (LMICs). We cannot achieve universal health coverage without palliative care, which is also a key component of the right to health and the United Nations Sustainable Development Goal for good health and well-being.

In 2014 the World Health Assembly passed the resolution 67.19, titled “Strengthening of palliative care as a component of comprehensive care throughout the life course.” This resolution for the first time called on all nations to strengthen palliative care and to ensure its availability. WHO is committed to helping achieve the vision of this resolution.

The Global Atlas of Palliative Care is a source of essential information on the status of palliative care worldwide. This second edition of the Global Atlas reveals some of the changes that have occurred since the first edition was published in 2014. For instance, we now have a better idea of how many people need palliative care worldwide. In the 1st edition a conservative estimate of 40 million has now been more accurately estimated as over 56.8 million, including 25.7 million in the last year of life.

The need for palliative care begins early in the course of a life-threatening illness. More patients are now receiving palliative care than six years ago, increasing from 16,000 services caring for 3 million patients to over 25,000 services caring for over 7 million patients. Still this is only about 12% of the need being met. Access to essential palliative medicines, including opioids, remains a major problem, especially in LMICs. Even with the widespread problems with opioid misuse in some countries, no one questions the importance of pain relief for those needing palliative care.

WHO is committed to working with key partners in palliative care, especially the Worldwide Hospice Palliative Care Alliance (WHPCA). This Atlas is a product of our official relations with the WHPCA. It is an important tool in WHO’s work with civil society organizations and governments to achieve the goals of the WHA palliative care resolution.

The COVID-19 pandemic has highlighted the importance of palliative care in all health care systems. The need for relief from severe suffering, the difficult decision making, and complicated grief brought on by the pandemic are exactly the types of problems that palliative care was designed to help address. The world will be a better place when palliative care is available to all who need it.

Dr Tedros Adhanom Ghebreyesus
Director General, World Health Organization

Foreword

The publication of this second edition of the Global Atlas of Palliative Care takes place in the midst of a global pandemic that has impacted every country in the world. The number of lives lost globally to the coronavirus are a harsh reminder of the need to ensure that care at the end of life is a priority for health care providers, regardless of their geographical location and health system.

Universal Health Coverage (UHC) is a concept that aims to ensure that countries develop a universally accessible health system for all citizens, one that meets population health needs and priorities. There is now general agreement that palliative care including access to essential medicines must be recognised as a population health need and that it should be viewed as an integral part of UHC. Indeed, palliative care, including access to pain treatment, is recognised as a human right. The continuum of UHC includes promotion, prevention, treatment, rehabilitation, and palliative care. Every country's health care system should include robust palliative care services as without it healthcare is not universal.

Despite the modest improvements in global development of palliative care that can be seen in the data contained in this new *Atlas*, inequities remain in the provision of palliative care globally both between and within countries. The majority of those needing palliative care worldwide remain those with non-malignant conditions. Whilst traditionally associated with the care of people with cancer, palliative care should be available to all who need it regardless of their diagnosis especially children and older people. Non-communicable diseases continue to rise and are the principal reason that people need palliative care. WHPCA is pleased to work in official relations with WHO through the department responsible for management of non-communicable disease.

Like its predecessor, this *Global Atlas* shines a light on the need for palliative care globally, and serves as a contemporary baseline, against which measurements can be made. It also provides much needed evidence that can be utilised to advocate for increased access to palliative care for all of those in need.

Dr Julie Ling,
Chair, Worldwide Hospice Palliative Care Alliance

Introduction

Stephen Connor, Claire Morris, Frank Brennan

This second edition of the Global Atlas of Palliative Care updates the current situation of global palliative care development since the original version was published in 2014. A lot has happened in the intervening years including the passage of the World Health Assembly's resolution on palliative care (WHA67.19). While progress is being made to meet the unmet need for palliative care globally the remaining gap in access to care is unacceptable.

The need for palliative care has never been greater and is increasing at a rapid pace due to ageing of the world's population, increases in cancer and other non-communicable diseases, and the recent emergence of COVID-19. By 2060 the need for palliative care at the end of life is expected to double.¹

Palliative care is underdeveloped in most of the world. Outside North America, Europe, and Australia, access to quality palliative care continues to be minimal even though 76% of the need is in low-and-middle income countries.

Since the early 1980s, the need for cancer palliative care has been progressively acknowledged worldwide. More recently, there is increased awareness of the need for palliative care for other chronic diseases or conditions such as HIV and AIDS, congestive heart failure, cerebrovascular disease, neurodegenerative disorders, chronic respiratory diseases, drug-resistant tuberculosis, injury, and diseases of older people. However, there remains a huge unmet need for palliative care for these chronic life-limiting health problems in most parts of the world.

The purpose of this *Atlas* is to continue to shine a light on the need for palliative care globally and to provide useful information for those wishing to increase access. This document addresses the following questions:

- What is palliative care?
- How many people are in need of palliative care worldwide?
- What are the main diseases requiring palliative care?
- What are the main barriers to palliative care?
- Where are the existing gaps?
- How well is palliative care developed in each country?
- Where is palliative care currently available?
- What are the models of palliative care worldwide?
- What resources are devoted to palliative care?
- What is the way forward?

What is palliative care for adults, for children?

WHO definition of palliative care

In 2002, the World Health Organization² established a revised definition of palliative care for adults and children, the introduction for which was modified in the WHO Palliative Care Resolution:

Palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual; Palliative care:

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

WHO definition of palliative care for children

Palliative care for children represents a special, albeit closely related field to adult palliative care. WHO's definition of palliative care appropriate for children and their families is as follows; the principles apply to other paediatric chronic disorders.³

Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family.

- It begins when illness is diagnosed and continues regardless of whether or not a child receives treatment directed at the disease.
- Health providers must evaluate and alleviate a child's physical, psychological, and social distress.
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.
- It can be provided in tertiary care facilities, in community health centres and even in children's homes.

Definition of Hospice⁴

“Hospice care is end-of-life care provided by health professionals and volunteers. They give medical, psychological and spiritual support. The goal of the care is to help people who are dying have peace, comfort and dignity. The caregivers try to control pain and other symptoms so a person can remain as alert and comfortable as possible. Hospice programmes also provide services to support a patient’s family.”



What is the relationship between curative and palliative care?

The aim of palliative care is to relieve suffering in order to improve quality of life for those with serious health related suffering. Persons receiving palliative care have a right to choose their treatments and may also receive curative treatments or interventions alongside palliative treatment. Palliative care professionals closely monitor symptoms and will advise if curative treatments may be adding to the person’s suffering thus allowing them to make informed choices as illness progresses or improves.

Why is palliative care a human rights issue?

In an article by Brennan⁵ (2007) the argument for palliative care as a human right was presented. Under international law, there are two main sources for this right: the right to health and the right to be free from cruel, inhuman and degrading treatment. The main statement of the right to health is contained in the International Covenant on Economic, Social and Cultural Rights (ICESCR) Article 12.1 (1966). Health care includes palliative care. The committee overseeing the ICESCR issued a general comment on the right to health that includes a number of core obligations of all signatory nations, irrespective of resources (2000). These obligations include access to health facilities, goods and services on a non-discriminatory basis; the provision of essential drugs as defined by WHO; and the adoption and implementation of a public health strategy. In the context of palliative care it is clear that patients with life-limiting illness should have access to appropriate health care, basic medications for symptom control and terminal care, as well as inclusion of palliative care in national health care policies. The UN Committee on Economic, Social and Cultural Rights stated that it is critical to provide “attention and care for chronically and terminally ill persons, sparing them avoidable pain and enabling them to die with dignity”⁶.

The WHO has stated that access to Essential Medicines is part of a nation’s human rights obligations.⁷ Fourteen palliative care medications are currently on the WHO Essential Drug List. In addition, the International Association for Hospice and Palliative Care (IAHPC), following a request from WHO, developed a list of Essential Medicines for Palliative Care.⁸

Many international organizations and bodies have called for the provision of palliative care as an essential component of the right to health care including the Canadian Senate (2000)⁹, the European Committee of Ministers (2003)¹⁰, the European School of Oncology (2004)¹¹, the Worldwide Palliative Care Alliance (2005)¹², the IAHPC (2008)¹³, UN Special Rapporteurs (2008, 2009)^{14 15}, the International Narcotics Control Board (2011)¹⁶ and the World Health Assembly (2014).¹⁷

World Health Assembly Resolution on Palliative Care

In 2014 the World Health Assembly unanimously passed resolution WHA.19 “Strengthening of Palliative Care as a Component of Comprehensive Care Throughout the Life Course.”¹⁷ This resolution calls on all member states to strengthen and integrate palliative care throughout their health care systems following the WHO public health model, which includes ensuring that policies are in place, comprehensive education on palliative care is available, essential palliative care medicines are available and affordable, and that programs are funded and implemented. (See Appendix 5 for full text)

WHO’s work to strengthen palliative care focuses on the following areas:

- integrating palliative care into all relevant global disease control and health system plans;
- developing guidelines and tools on integrated palliative care across disease groups and levels of care, addressing ethical issues related to the provision of comprehensive palliative care;
- supporting Member States in improving access to palliative care medicines through improved national regulations and delivery systems;
- a special focus on palliative care for people living with HIV, including development of guidelines;
- promoting increased access to palliative care for children (in collaboration with UNICEF);
- monitoring global palliative care access and evaluating progress made in palliative care programmes;
- developing indicators for evaluating palliative care services;
- encouraging adequate resources for palliative care programmes and research, especially in resource-limited countries; and
- building evidence of models of palliative care that are effective in low- and middle-income settings.

Palliative Care and Universal Health Coverage

The 2015 UN Sustainable Development Goals are the roadmap to improving life on earth. The continuum of universal health coverage under the United Nations Sustainable Development Goal number three (3.8) includes *Promotion, Prevention, Treatment, Rehabilitation, & Palliative Care*. There is no ‘universal’ health coverage without palliative care. All nations need to include palliative care in their plans for Universal Health Coverage.

How many adults and children are in need of palliative care worldwide?

Felicia Knaul*, Lukas Radbruch*, Stephen Connor, Liliana de Lima, Hector Arreola-Ornelas, Oscar Mendez Carniado, Xiaoxiao Jiang Kwete, Afsan Bhadelia, Julia Downing, Eric L. Krakauer

Executive Summary

Worldwide, over 56.8 million people are estimated to require palliative care every year including 31.1 million prior to and 25.7 million near the end of life. The majority (67.1%) are adults over 50 years old and at least 7% are children. The majority (54.2%) are non-decedents who need palliative care prior to their last year of life. The burden of severe illness and health related suffering, and the corresponding need for palliative care, are immense. Yet palliative care is still not accessible by most people in need, especially in low and middle-income countries (LMICs).

The majority of adults in need of palliative care (76%) live in LMICs, and the highest proportion are in countries of low-income. Non-communicable diseases account for almost 69% of adult need. Among adults, the illnesses and conditions that generate most serious suffering requiring palliative care interventions are cancer, HIV/AIDS, cerebrovascular, dementias, and lung diseases.

The Western Pacific, Africa, and Southeast Asia regions account for over 64% of adults in need of palliative care, while the European and Americas regions have 30% and the Eastern Mediterranean region account for 4%. The greatest need per population is in the Africa region (related to the high incidence of HIV/AIDS) followed by Europe and the Americas regions that have older populations. In nearly all world regions, adults whose need for palliative care is generated by non-malignant conditions constitute the greatest need, followed by cancer. Only in the Africa region HIV/AIDS predominates over malignant and other non-malignant diseases.

The vast majority (>97%) of children aged 0-19 years in need of palliative care live in LMICs. Children with HIV/AIDs and congenital malformations represent almost 46% of the need for palliative care, followed by children with extreme prematurity and birth trauma (almost 18%) and injuries (16%). The Africa region accounts for over half the need for palliative care among children, followed by South East Asia (20%), the Eastern Mediterranean (12%) and the Western Pacific (8%). Europe and the Americas together account for only 9% of child palliative care need. On a per capita basis, the need for children's palliative is by far the highest in the Africa region followed by the Eastern Mediterranean. Palliative care need for children occurs mostly due to progressive non-malignant diseases, which account for the greatest need all regions except Africa, where palliative care need is mostly associated with HIV. Cancer accounts for a smaller percentage of overall need in children.

* Joint first authors

Introduction

The World Health Assembly resolved that palliative care is an ethical responsibility of health systems and a key component of universal health coverage (UHC). The effective integration of palliative care into health systems requires accurate assessment of global palliative care need.¹⁷ Up-to-date estimates enable health care planners, implementers and managers to organize the resources and training necessary to respond appropriately to evolving need.¹⁷ Over time, improvements in prevention, early detection and treatment alter the types and distribution of palliative care needs for both decedents and non-decedents.

This Atlas, now in its second edition, takes up the need to assess palliative care need at regular intervals¹⁸ and provides updated estimates to 2017. With time, improvements in prevention, early detection and treatment alter the types and distribution of palliative care needs for both decedents and non-decedents. The estimates are based on the concept of serious health-related suffering (SHS) pioneered by the Lancet Commission on Global Access to Palliative Care and Pain Relief. Suffering is health-related when it is associated with illness or injury of any kind, and it is moderate or severe when it cannot be relieved without the intervention of a health care professional, and when it compromises physical, social or emotional functioning. Palliative care should be focused on relieving the serious health or illness related suffering that is associated with serious health problems or the end of life. SHS is a proxy for palliative care need.

Summary of methodological updates:

This second edition considerably expands the conceptualization and methodology for estimating palliative care need compared to the first edition of the Atlas, by using much improved methods developed in the 2017 report of the Lancet Commission on Global Access to Palliative Care and Pain Relief.¹⁹ The SHS methodology is detailed in both the Commission report and data appendix.¹⁹ The current estimate includes several updates to the methodology put forward in the 2017 report and these are available through the website of the International Association for Hospice and Palliative Care - IAHPC (www.hospicecare.com).

The key methodological differences, as compared to the first Atlas, are as follows:

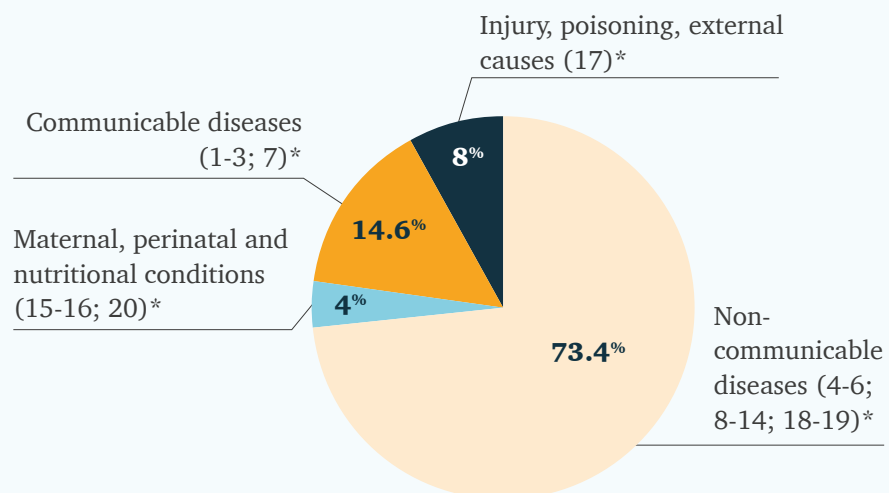
- The number of diagnostic groups needing palliative care increases from 18 to 20 (Alzheimer and other dementias, arteriosclerosis, cerebrovascular disease, chronic ischemic heart disease, congenital malformation, degenerative CNS disease, haemorrhagic fevers, HIV, inflammatory CNS disease, injury, leukaemia, liver disease, low birth weight-premature birth-birth trauma, lung disease, malignant neoplasm, malnutrition, musculoskeletal disorder, non-ischemic heart disease, renal failure, tuberculosis)
- Injury (including poisoning and external causes) has been added in this edition and generates 6.4% of the need.
- The number of symptoms used to identify palliative care need increased from only one (pain) to 16 (including differentiation between mild pain and moderate to severe pain in addition to anxiety/worry, bleeding, confusion/delirium, constipation, dementia, depressed mood, diarrhoea, dry mouth, fatigue, itching, nausea/vomiting, shortness of breath, weakness and wounds).

- While the first Atlas did a rough estimate of total need by doubling the decedent (mortality) need to account for need prior to the end-of-life, the Lancet Commission SHS methodology separately estimates those needing palliative care in their last year of life (decedents) and those needing palliative care prior to their last year of life (non-decedents) and this Atlas estimate considers both for 2017,
- Days of suffering were calculated for each of the 16 symptoms and for each condition, by multiplying the number of patients with the possibility of having the symptom as well as the average duration of the symptom in days (days of suffering were added up assuming no overlaps, meaning that a day with both pain and nausea experienced would be counted as two days of suffering),
- Whereas the original Atlas only used mortality data to estimate the need for palliative care at the end-of-life, the SHS-based estimates primarily combine mortality and prevalence data extracted from the Institute for Health Metrics and Evaluation Global Burden of Disease Study 2017, and for specific non-decedent estimates, additional global databases including from UNAIDS and International Agency for Research on Cancer (IARC).
- World Bank Income Groups are from WB 2017-2018 Income Group Classification, and Population data are from IHME 2017 Population Estimates.
- Country level estimates on need for palliative care can be found in the resource sections of the WHPCA and IAHPC websites.

Overall Mortality Worldwide

As a point of reference, in 2017²⁰ there were 55,945,730 deaths from 195 reporting countries worldwide. The great majority of those deaths, 73.4%, were due to non-communicable diseases. (Fig 1).

Figure 1
Distribution of major causes of death worldwide for all ages, males and females (2017)*

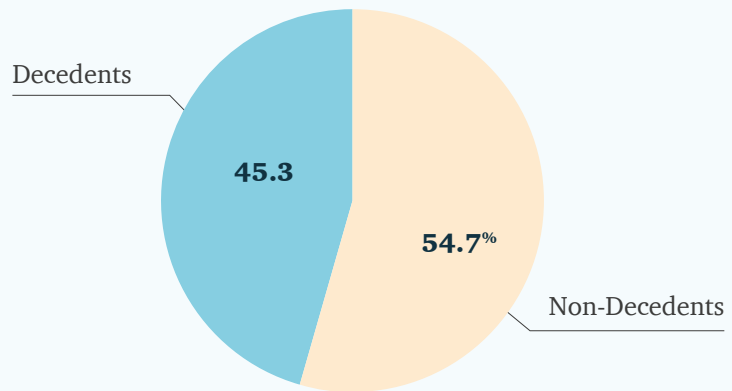


*Based on data for 354 diseases and injuries and 3484 sequelae

Estimates of people in need of palliative care worldwide

The total, all age, global need for palliative care is 56,840,123 people including both decedents and non-decedents. The need for non-decedents [31,100,719] was higher than for decedents [25,739,404] (Fig 2). Palliative care was needed for 45.3% of all deaths in 2017.

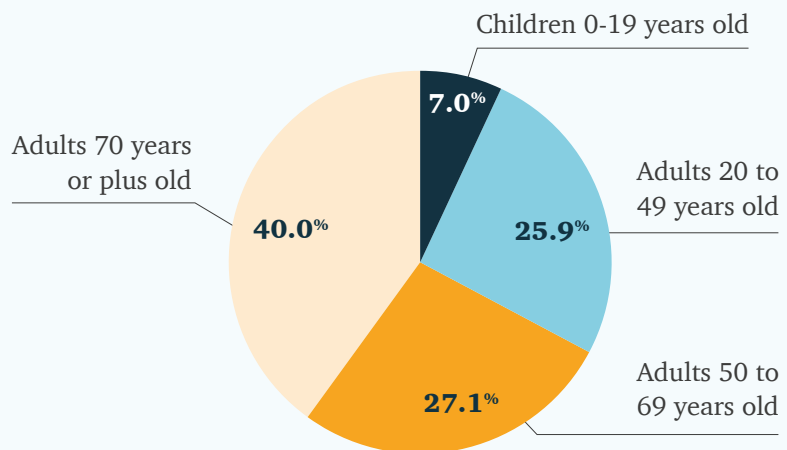
Figure 2
Need for palliative care for decedents and non-decedents, (all ages all sexes; 2017)



N = 56,840,123 people

Approximately 40% of patients in need of palliative care are aged 70 years or older, 27% aged 50-69 and, almost 26% aged 20-49 and only 7% are children (0-17 years) (Fig 3).

Figure 3
Worldwide need for palliative care by age group (2017)



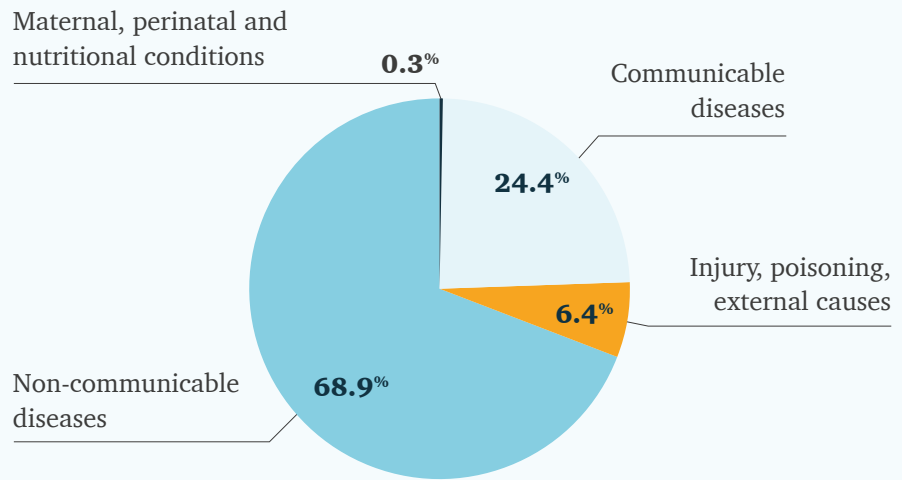
N = 56,840,123 people

Adults in need of palliative care worldwide

Among adults (aged 20 years and over), 68.9% (36.5 million people) of decedent and non-decedent palliative care need is associated with a non-communicable disease. HIV/AIDS, haemorrhagic fever, tuberculosis, and some injuries also account for an important part of palliative care for adults (Fig 4).

Total need for palliative care for adults was 52,883,093 and there was nearly equal gender distribution (female 49%).

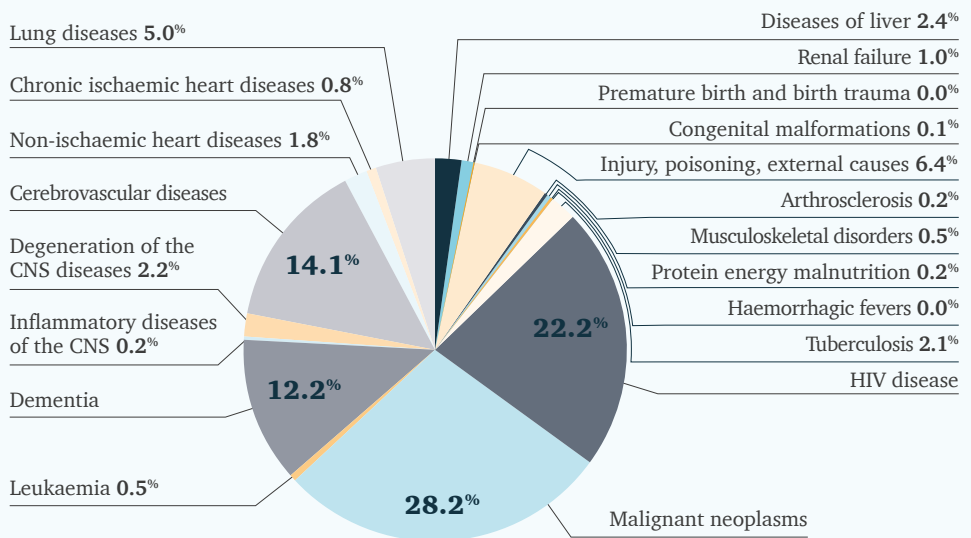
Figure 4
Worldwide need for palliative care for adults, by major diagnostic group (20+ years, 2017)



N = 52,295,120 adults

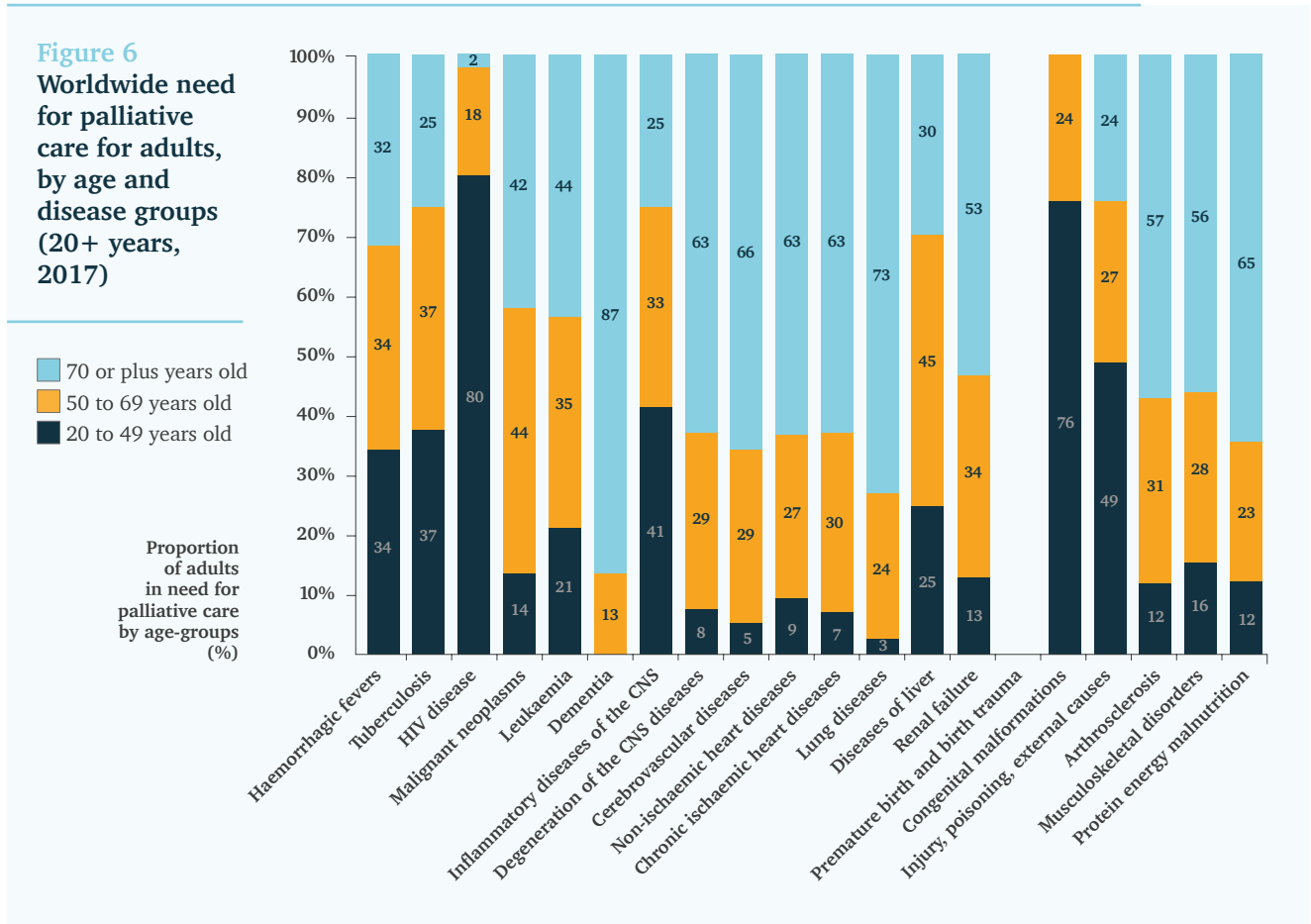
Although the largest single disease group accounting for adult palliative care is cancer, over 70% of the need is for other conditions as shown in Figure 5. HIV, cerebrovascular diseases, and dementia are the most frequent.

Figure 5
Worldwide need for palliative care for adults by disease groups (20+ years 2017)



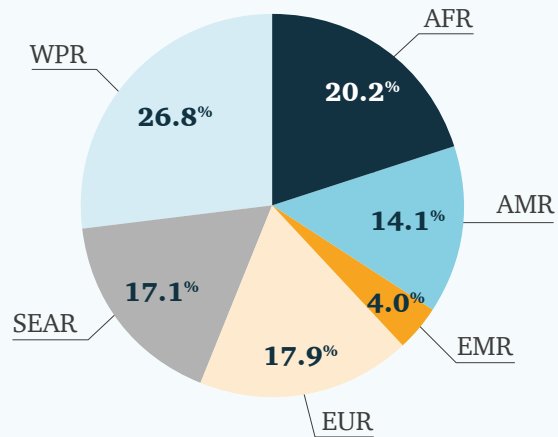
N = 52,883,093 adults

The need for palliative care varies by age group (Fig 6) for all 20 diagnostic groups with younger adults suffering more from HIV, congenital conditions, injury, and inflammatory conditions.



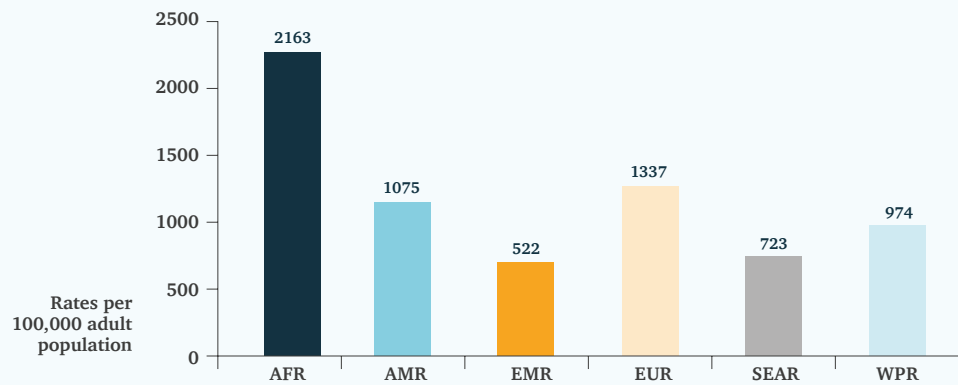
Using the WHO Member States regional groupings, over a quarter of adults needing palliative care (26.8%) live in the Western Pacific Region, followed by the Africa region (20.2%), Europe (17.9%) and South East Asia (17.1). The figures for the Americas and Eastern Mediterranean regions are 14.1% and 4.0%, respectively (Fig. 7). However, the Africa Region has the highest number of adults in need of palliative care per 100,000 adult population, followed by Europe and the Americas regions (Fig. 8).

Figure 7
Worldwide need for palliative care for adults by WHO region (20+ years, 2017)



N = 52,883,093 adults

Figure 8
Worldwide need for palliative care for adults, by WHO region and per 100,000 population (20+ years; 183 countries; 2017)

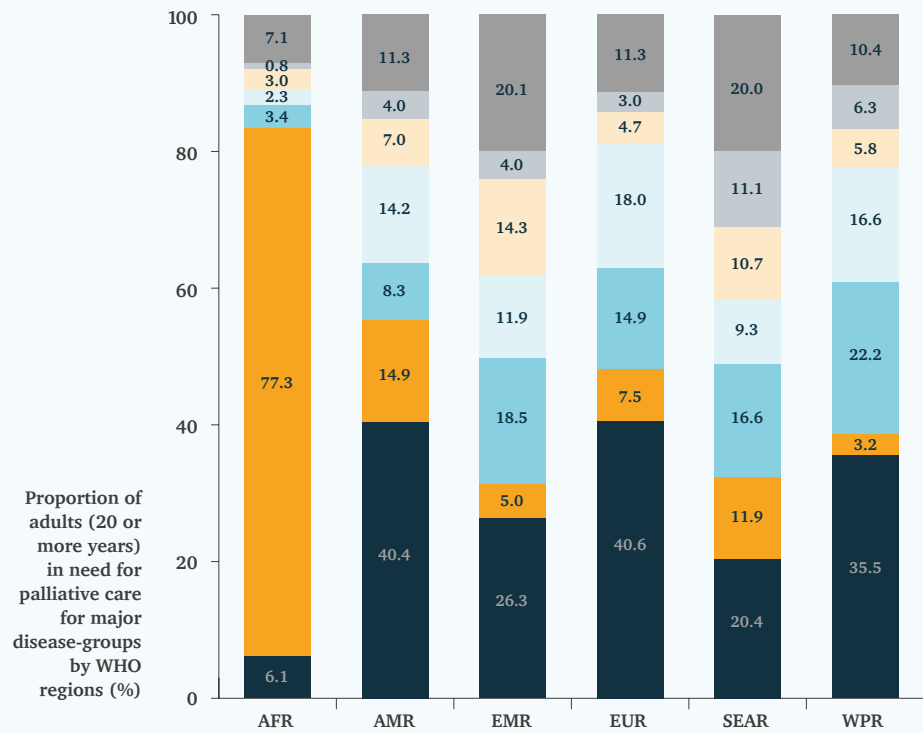


N = 183 Countries

To analyse by region, the need for palliative care is grouped into seven categories: cancers, HIV/AIDS, stroke, dementias, injuries, and other non-malignant diseases. In all regions except Africa the highest proportion of adults in need of palliative care have other non-malignant disease. HIV/AIDS predominates in the African Region. The proportion of adults in need of palliative care for cancer is relatively high for all regions. It ranges from 6.1% in the African Region to 41.3% in the European and 40.8% in the American Region (Fig. 9)

Figure 9
Worldwide need for palliative care for adults, by WHO region and disease categories (20+ years; 183 countries; 2017)

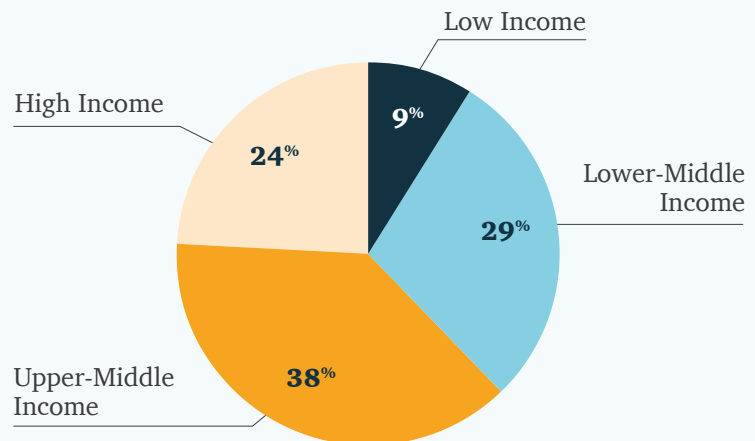
- Malignant neoplasms (cancers)
- HIV disease
- Cerebrovascular diseases
- Dementia
- Injury, poisoning, external causes
- Lung diseases
- Other



N = 183 Countries

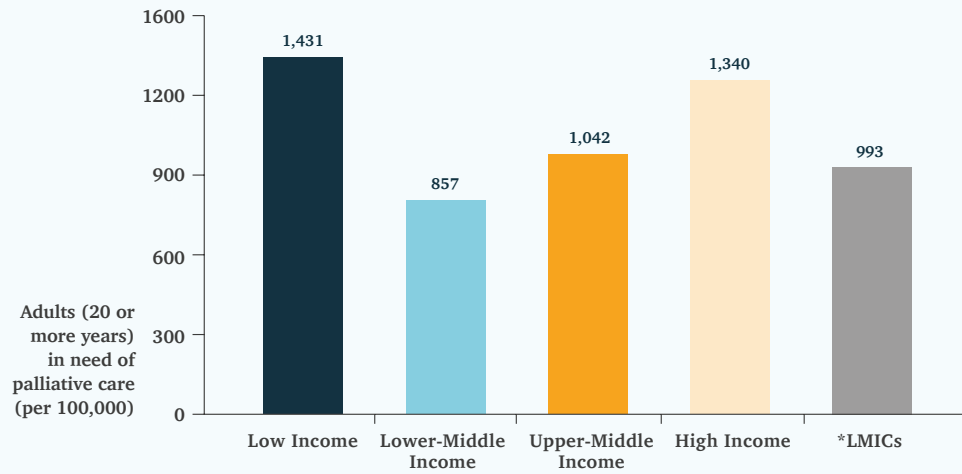
The great majority, 76%, of the 53 million adults in need of palliative care live in low- or middle-income countries (LMICs) (Fig. 10). Most (67%) live in the upper and lower middle-income groups. However, the highest ratios per 100 000 adult population in need of palliative care are found in the low-income countries (Fig. 11). This could be an indicator of more SHS from preventable disease complications or preventable deaths related to inadequate or overwhelmed health care systems in low-income countries. The illness conditions that most often generate a need for palliative care in decedents and non-decedents differ between high income (HICs) and LMICs. There are many more non-decedents with HIV/AIDS who need palliative care in LMICs than in HICs (Figs 12 & 13).

Figure 10
Worldwide need for palliative care for adults by World Bank income category (20+ years; 2017)



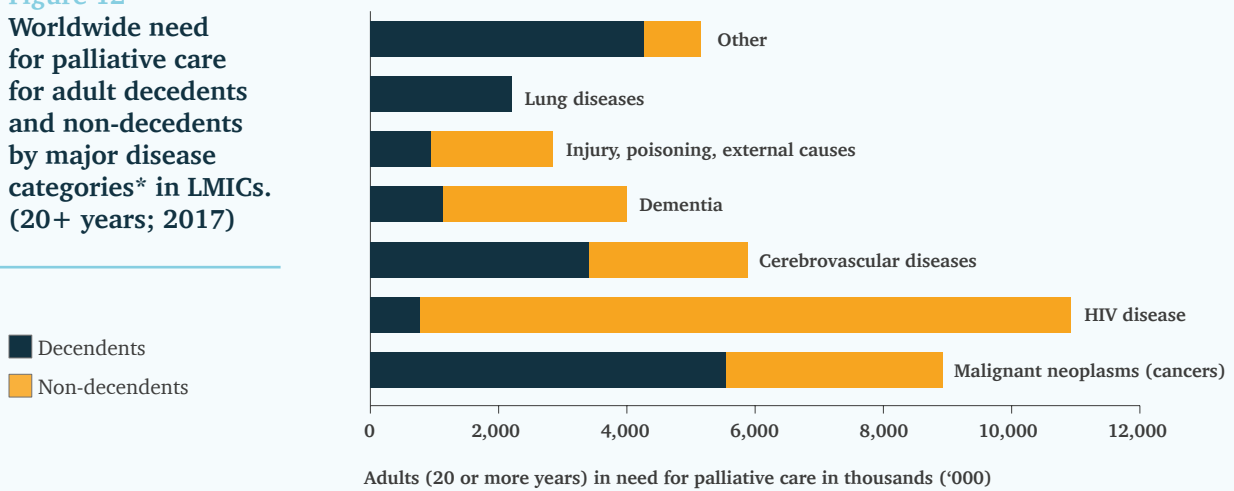
N = 52,883,093 adults

Figure 11
Worldwide need for palliative care for adults per 100,000 population by World Bank income category (20+ years; 2017)



N = 183 Countries

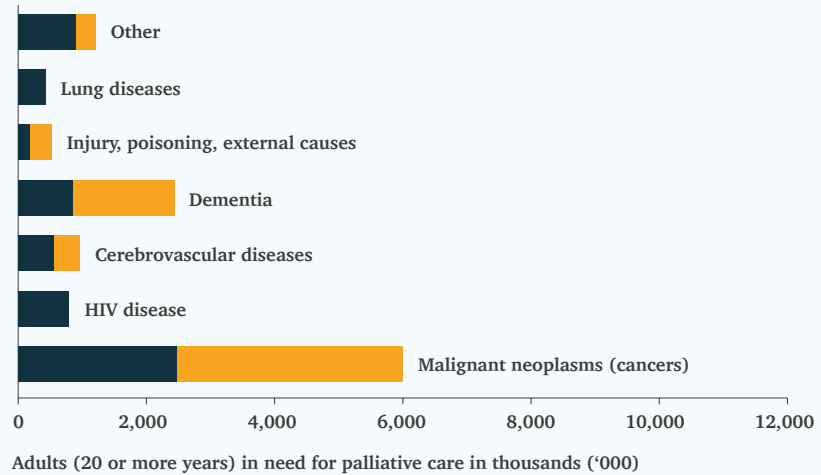
Figure 12
Worldwide need for palliative care for adult decedents and non-decedents by major disease categories* in LMICs. (20+ years; 2017)



N = 40,311,610 adults

Figure 13
Worldwide need for palliative care for adult decedents and non-decedents by major disease categories* in HICs. (20+ years; 2017)

Decedents
Non-decedents



N = 12,571,482 adults

* 20 Health conditions: 1:Haemorrhagic fevers; 2:Tuberculosis; 3:HIV disease; 4:Malignant neoplasms; 5:Leukaemia; 6:Dementia; 7:Inflammatory diseases of the CNS; 8:Degeneration of the CNS diseases; 9:Cerebrovascular diseases ; 10:Non-ischaeamic heart diseases; 11:Chronic ischaemic heart diseases; 12:Lung diseases; 13:Diseases of liver; 14:Renal failure; 15:Premature birth and birth trauma; 16:Congenital malformations; 17:Injury, poisoning, external causes; 18:Arthrosclerosis; 19:Musculoskeletal disorders; 20:Protein energy malnutrition

Maximum days of suffering were calculated for each of the 16 symptoms and for each condition, by multiplying the number of patients with the possibility of having the symptom as well as the average duration of the symptom in days. The global total sum of those days of suffering adds up to over 12,100 million days for decedents (Fig. 14) and 7,600 million days for non-decedents (Fig 15). Note that this does not consider overlap if several symptoms occurred simultaneously.

Figure 14
Percentage of days that adults worldwide experience serious health related suffering for 20 health conditions for 16 symptoms by decedents (20+ years; 2017)

N = 3091.2 millions days

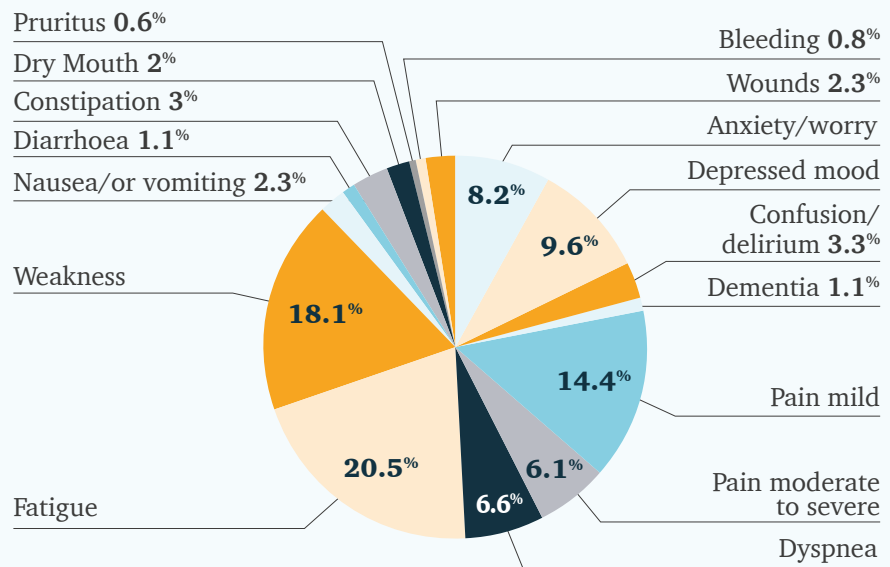
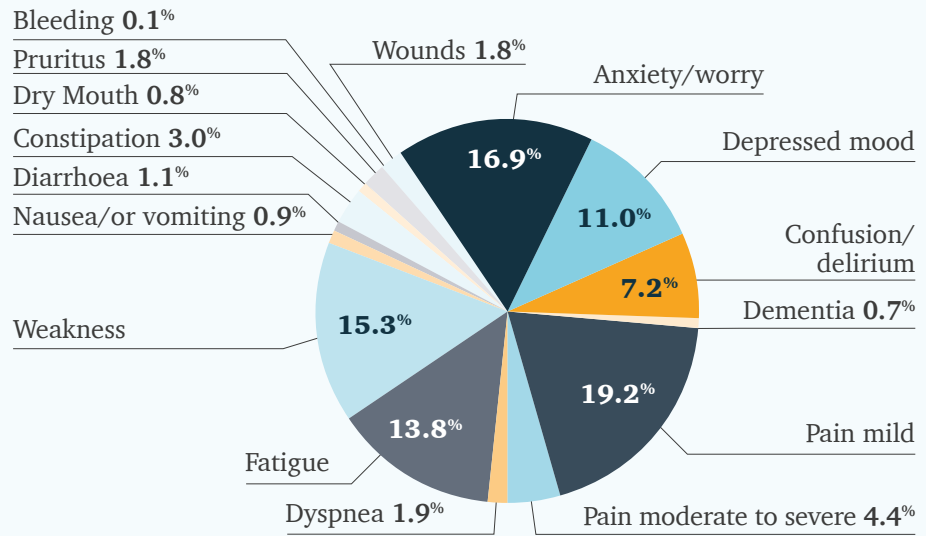


Figure 15
Percentage of days that adults worldwide experience serious health related suffering due to 20 illness conditions for *16 symptoms, non-decedents (20+ years; 2017)



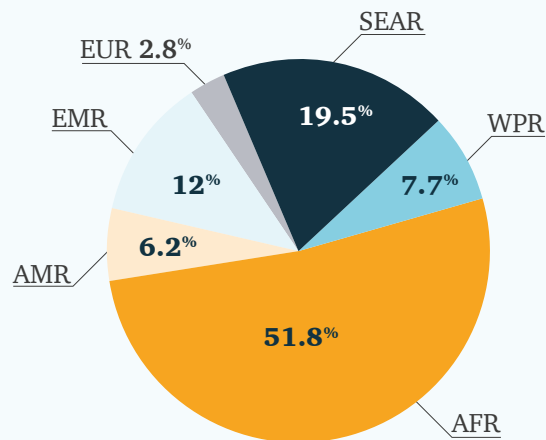
N = 9069.9 millions days

Children in need of palliative care worldwide

The estimated global total number of children in need of palliative care in 2017 is almost 4 million (N = 3,957,030 children). Children and adolescents aged 0 – 19 comprise 7% of the total global palliative care needs (Fig. 3). There is a slightly higher proportion of males (53.8%) than females.

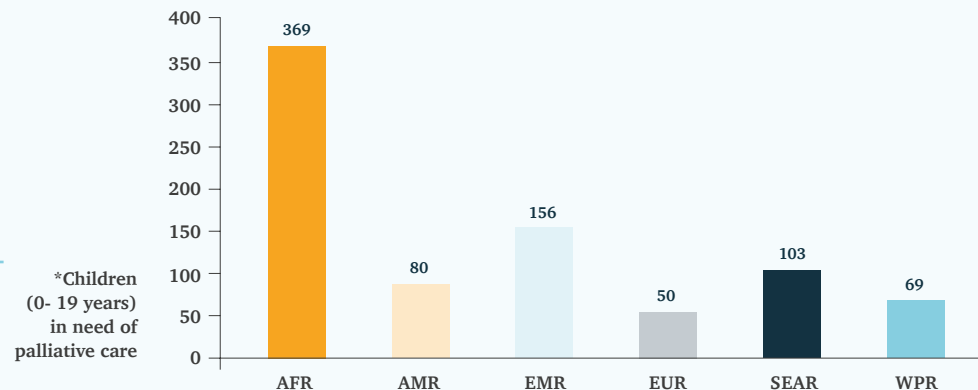
The majority of children in need of palliative care are in the African and the South East Asian Regions (51.8% and 19.5% respectively), followed by the Eastern Mediterranean (12%), Western Pacific regions (7.7%), and Region of the Americas (6.2%). In contrast the European region has only 2.8% of the total (Figure 16). The African, Eastern Mediterranean, and South East Asian regions have the highest rates per 100,000 children (369, 156, 103 respectively) (Figure 17).

Figure 16
Worldwide need for palliative care for children by WHO region (0-19 years, 2017)



N = 3,957,030 children

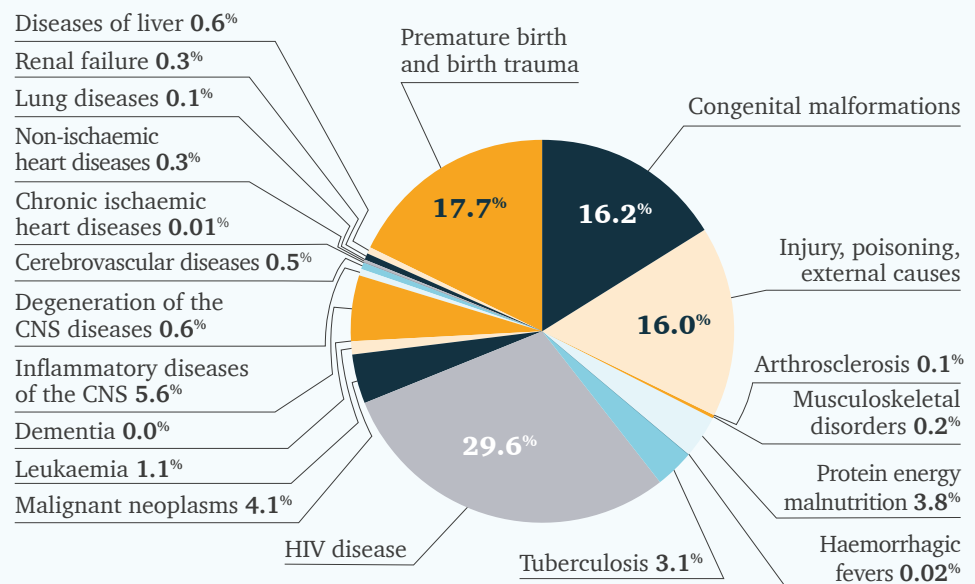
Figure 17
Worldwide need for palliative care for children per 100,000 population by WHO Region (0-19 years; 2017)



The illness condition that generates the greatest need for palliative care among children is HIV/AIDS (29.6%), followed by premature birth and birth trauma (17.7%) congenital anomalies (16.2%), and injuries (16%). Cancers only account for 4.1% (Fig. 18).

Progressive non-malignant diseases excluding HIV/AIDS, generate the greatest need for palliative care among children in all WHO regions except Africa. Cancer generates a small proportion of the need in every region (Fig. 19).

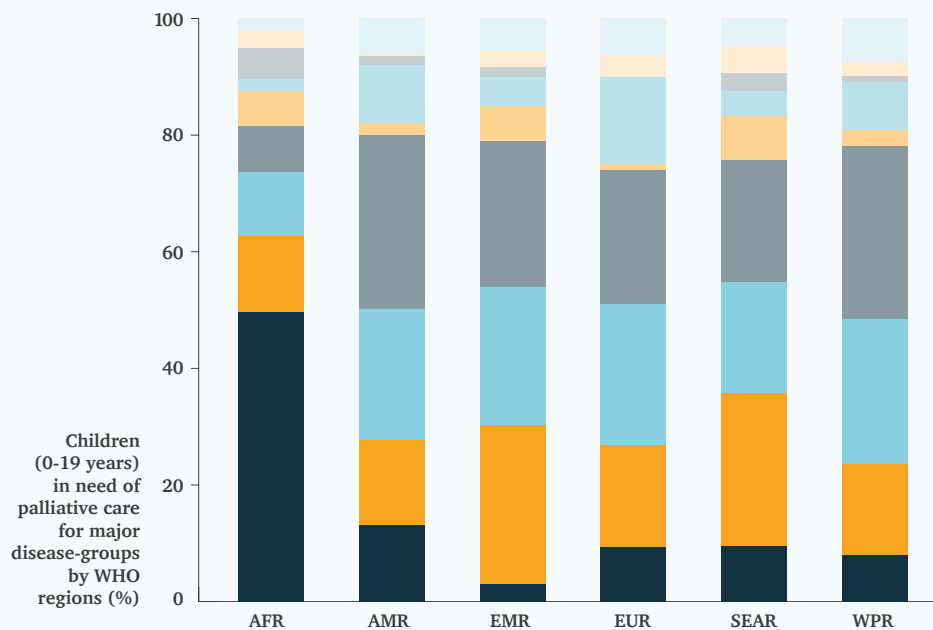
Figure 18
Worldwide need for palliative care for children by disease groups (0-19 years; 2017)



N = 3,957,030 children

Figure 19
Worldwide need for palliative care for children (0-19) by WHO regions and disease categories (183 countries; 2017)

- HIV disease
- Premature birth and birth trauma
- Congenital malformations
- Injury, poisoning, external causes
- Inflammatory disease of the CNS (meningitis, etc)
- Malignant neoplasms (cancers)
- Protein energy malnutrition
- Tuberculosis
- Other



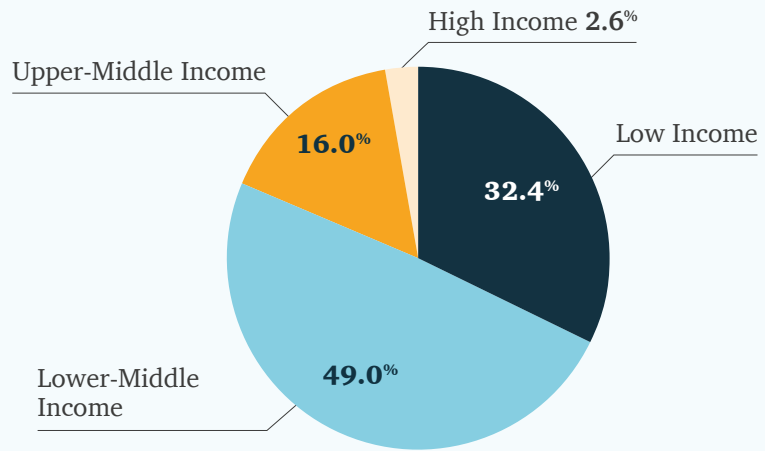
N = 183

* 20 Health conditions: 1:Haemorrhagic fevers; 2:Tuberculosis; 3:HIV disease; 4:Malignant neoplasms; 5:Leukaemia; 6:Dementia; 7:Inflammatory diseases of the CNS; 8:Degeneration of the CNS diseases; 9:Cerebrovascular diseases; 10:Non-ischaemic heart diseases; 11:Chronic ischemic heart diseases; 12:Lung diseases; 13:Diseases of liver; 14:Renal failure; 15:Premature birth and birth trauma; 16:Congenital malformations; 17:Injury, poisoning, external causes; 18:Arthrosclerosis; 19:Musculoskeletal disorders; 20:Protein energy malnutrition

The vast majority of children (>97%) in need of palliative care live in LMICs. Almost half (48.9%) are in the lower middle-income countries and almost one third in low-income countries (Fig. 20). There is an inverse relationship between the rates of children in need of palliative care and country income-level. Lower income countries have the highest ratios (Fig. 21).

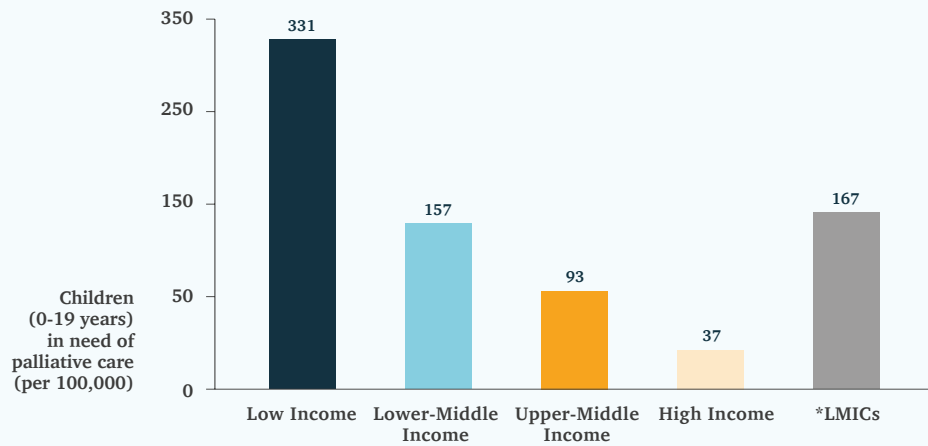
The illness conditions that most often generate a need for palliative care in decedent and non-decedent children differ between HICs and LMICs. There are much higher numbers of non-decedent children with injuries, HIV, and congenital malformations in LMICs (Figs 22 & 23).

Figure 20
Worldwide need for palliative care for children (0-19) by income group (183 countries; 2017)



N = 3,957,030 children

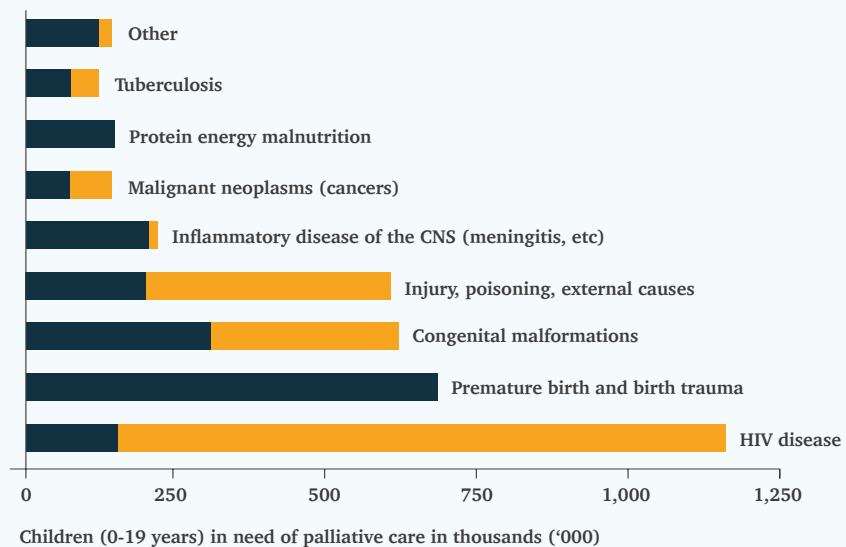
Figure 21
Worldwide need for palliative care for children per 100,000 population by World Bank income category (0-19 years; 2017)



N = 183 countries

Figure 22
Worldwide need for palliative care for children (0-19), decedents and non-decedents, by major disease categories* in LMICs (2017)

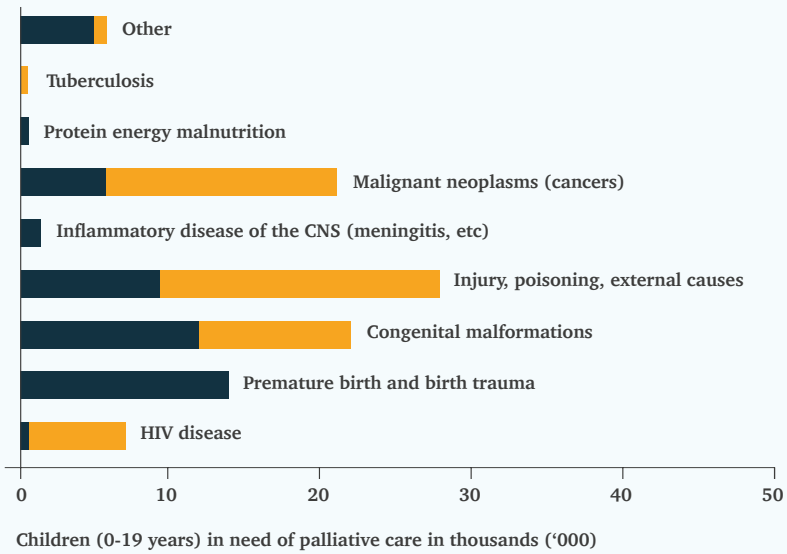
■ Decedents
■ Non-decedents



N = 3,854,051 children

Figure 23
Worldwide need for palliative care for children (0-19), decedents and non-decedents, by major disease categories* in HICs (2017).

■ Decedents
■ Non-decedents



N = 102,979 children

Maximum days of suffering were calculated for each condition and for each of the 16 symptoms occurring in these conditions in the same way as for adults, by multiplying the number of children with the possibility of having the symptom as well as the average duration of the symptom in days. For children and adolescents, the global total sum of those days of suffering adds up to over 360 million days for decedents (Fig. 24) and 385 million days for non-decedents (Fig 25). Note that this does not consider overlap if several symptoms occurred simultaneously.

Figure 24
Percentage of days that children (0-19) worldwide experience serious health-related suffering for 20 health conditions for *16 symptoms by decedents (2017)

N = 360.65 millions days

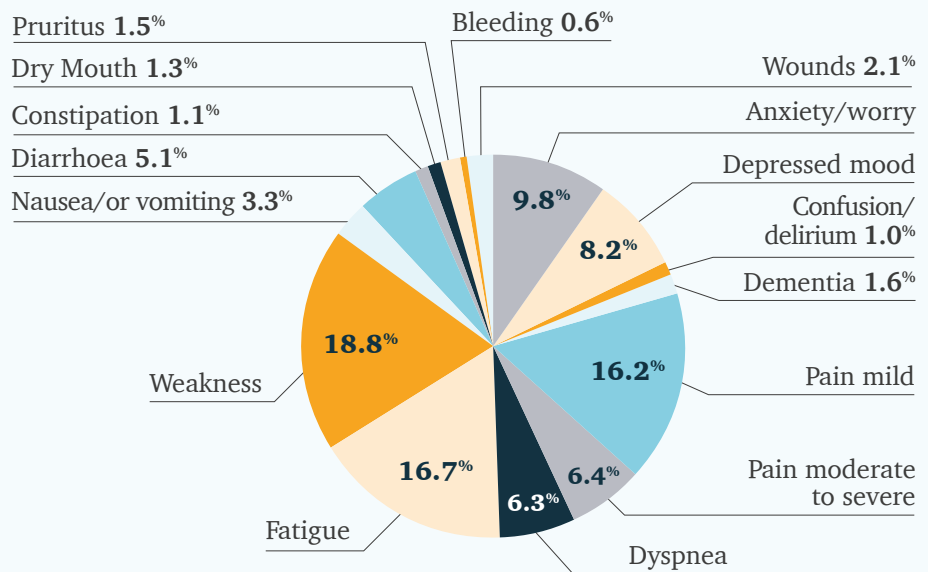
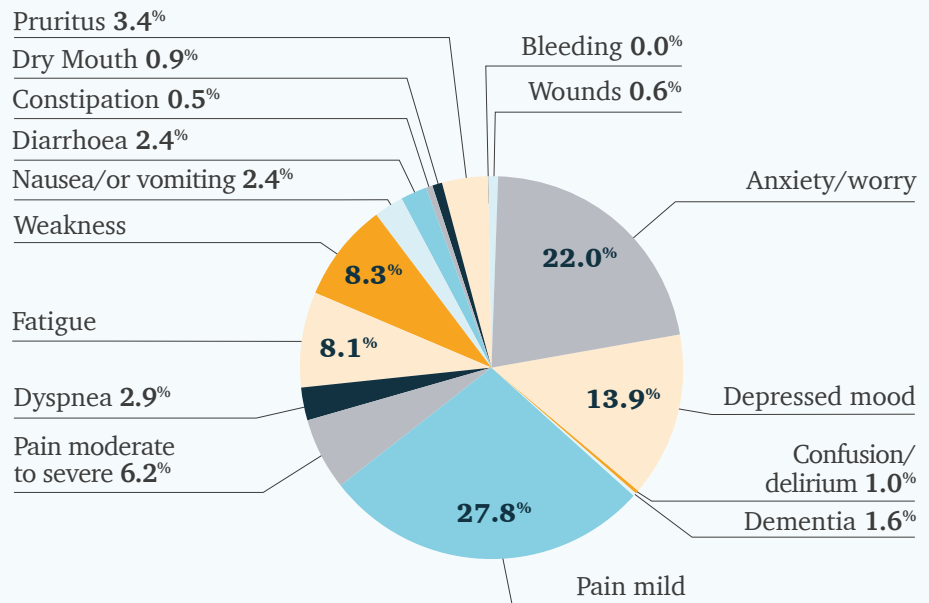


Figure 25
Percentage of days that children (0-19) worldwide experience serious health related suffering by 20 illness conditions for *16 symptoms by non-decedents (2017)



N = 385.43 millions days

What are the main barriers to palliative care development?

James Cleary, Barbara Hastie, Richard Harding, Ernesto Jaramillo, Stephen Connor, Eric Krakauer

Palliative care development follows a public health model developed by the WHO that emphasizes policy, education, medication availability, and implementation.²¹ There are many barriers to achieving each of these components.

Policy

Without policies that support the provision of palliative care it is quite difficult for any palliative care to develop. In some countries there is no government support whatsoever for palliative care. In others, such as Romania and Zimbabwe, charitable palliative care services have developed. But even in these cases permission to operate has to be granted. Policy is therefore seen as the fundamental component, because without it other changes cannot be introduced. Types of policies needed include:

- laws that acknowledge and define that palliative care is part of the health-care system;
- national standards defining how palliative care programs must operate;
- clinical guidelines for the delivery of palliative care services;
- establishment of palliative care as a recognized medical specialty/sub-specialty;
- regulations that establish palliative care as a recognized type of health-care provider with accompanying licensing provisions;
- a national strategy on palliative care implementation.

A review of the current global status of all palliative care policy development was done by Clelland et al, 2020²² and found only 55 countries with any national plan for palliative care.

Education

The vast majority of health professionals worldwide have little or no knowledge of the principles and practices of palliative care. A growing body of knowledge has been accumulated over the past 50 years on the science of palliative care and palliative medicine. There are now at least 14 professional journals devoted to palliative care, a growing body of peer-reviewed literature, and numerous books, internet sites, blogs and forums devoted to all aspects of palliative care (see Appendix 2 for listings).

Palliative care education is needed at three levels:

- Basic palliative care training for all health professionals and paraprofessionals including physicians, nurses, mental health professionals, clergy, volunteers and therapists;

- Intermediate training for those routinely working with patients with life-threatening illnesses;
- Specialist palliative care training for patients with more complex symptom management needs and for those who will teach palliative care and do research.

Curricula for these three levels exist, however, there is no consensus on the amount of training needed and most of the existing educational programmes are in English. There is also a need to carry out community education and awareness campaigns about palliative care at the same time as services are established. When services are delivered patients and families also need extensive training on how to provide care including personal care, body mechanics, symptoms to expect and how to manage, along with signs/symptoms of impending death and so forth.

Medication Availability

Most medications in the *WHO Model List of Essential Medicines for Pain and Palliative Care, 21st Edition 2019*,²³ especially controlled substances namely, opioids, are required for the delivery of quality palliative care. Access to opioid medications for pain control is an enormous problem worldwide. Over eighty per cent (84.25%) of the world's population lacks adequate access to opioid medications for pain control. Australia, Canada, New Zealand, the United States, and several European countries accounted for more than 90% of the global consumption of opioid analgesics while Low-and-Middle-Income Countries (LMICs) consumed only 10% of global opioids.^{24 25 26}

The UN Single Convention on Narcotic Drugs,²⁷ approved by most countries in 1961, called for balance between mitigating diversion of licit opioids and other psychoactive substances while also allowing for adequate provision of these drugs for medical and scientific use. Since that time, the major focus has remained on control of illicit use of these drugs, and even restricting licit medicines, with little emphasis on enhancing access for medical and scientific use. The worldwide palliative care community and related human rights organizations have advocated for balance to be restored by paying equal attention to both medical use and prevention of illicit use. In 2016, the Commission on Narcotic Drugs (CND) included “access to controlled medicines” as an area of focus in the UN General Assembly Special Session and High-Level Meeting on the World Drug Problem.²⁸ A subsequent 2019 Ministerial Declaration²⁹ reinforced the need and commitment to address the pathos of disparity in access and availability of controlled substances for medical and scientific purposes, especially for pain and palliative care.

While the true need for opioids per capita remains under debate, and will vary by country depending on age, disease rates, causes of death and many other factors, Seya et al³⁰ published an estimate of opioid need for 188 countries. They used average usage in the 20 top countries in the Human Development Index (HDI) as a reference point for development of an adequacy of consumption measure (ACM). According to this analysis 83% of the world's countries have low to non-existent access to opioids, 4% have moderate access, and 7% have adequate access, while for the remaining 6% of countries insufficient data is available. Notably, recently, Scholten et al³¹ extended this investigation by using the “adequacy of opioid consumption” (AOC) index and compared it across countries with high HDI. Indeed, the average opioid analgesic consumption of the top-20 countries

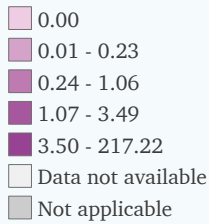
of the HDI increased from 84 morphine milligram equivalents per capita (2000) to 256 morphine milligram equivalents per capita (2015). However, the overall consumption for all countries, due to limited access in most countries was only about 33.25 mg per capita and the consumption of morphine, mainly used in palliative care was less than 5 mg per capita (Table 1).

Key indicators of opioid availability are the reports of opioid usage that are published by the International Narcotics Control Board (INCB)²⁴. There is enormous variability in consumption per capita around the world and many barriers to increasing the availability and consumption of opioids for medical and scientific use. These barriers include overly strict regulation, limitations on available forms of medication particularly oral opioids, lack of supply and distribution systems, limitations on who can prescribe, fear of law enforcement intervention into medical use, and so forth. In this regard, in using the INCB data for practical application, Gilson et al³² revealed the relevance of a morphine equivalence (ME) metric in demonstrating the extent that morphine consumption relates to total consumption of other widely used licit opioids. It is that metric that is reflected in the maps below (Figures 28 and 29) and are shown for global and country comparisons. Further opioid consumption data and interactive graphics can be found at the Indiana University Walther Centre in Global Palliative Care & Supportive Oncology website at painpolicy.iu.edu

Table 1
2017 Global Opioid
Consumption Data
(International Narcotics
Control Board)

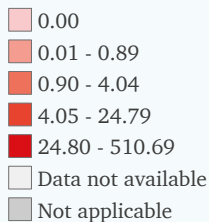
Population	7510990456
Global Morphine Consumption (mg/person)	4.9281591
ME in mg/person ALL Opioids Minus Methadone	
Morphine	4.9281591
Codeine	0.17824061
Fentanyl	15.0297903
Hydromorphone	2.21417603
Pethidine	0.06187702
Oxycodone	10.83745
Total ME in mg/person minus Methadone	33.2496931

Figure 28
Morphine use
worldwide
(Mg/Capita) 2017



Total Morphine consumption per capita
Consumption in mg/person

Figure 29
Morphine equivalent
total opioid use
worldwide (minus
methadone) 2017



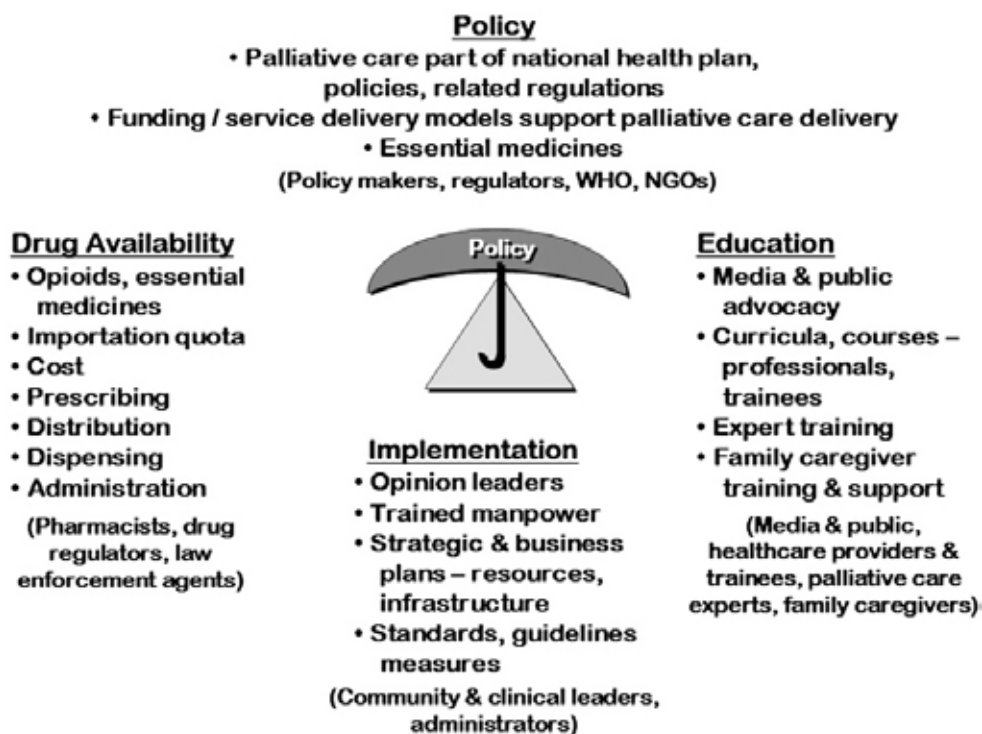
Total Opioid consumption (minus Methadone) per capita
Consumption in mg/person

Implementation

Palliative care programme development has been very uneven internationally (see Chapter 4 for mapping of existing services) and is correlated with Human Development Index levels, Universal Health Coverage, and World Bank Income Group.³³ Without policy support for palliative care and funding mechanisms, growth is restricted to whatever is achieved by pioneers making sacrifices to create hospice and palliative care services in their communities. To reach the huge numbers of people with palliative care needs that are not receiving the services they need will require further integration into existing health care systems, including primary care and long-term care. Home based care is especially important and should be prioritised over creating new facilities. Some inpatient care is needed but the vast majority of palliative care services can be delivered in the places people call home.

All these areas are related and will require education, essential medicines, policies, and the social and political support needed to make palliative care a priority and a reality throughout the world

Figure 30
Public health model
for palliative care
development³⁴



Health Workforce Need

Reaching over 56 million people needing palliative care globally would require a major increase in the professional and para-professional workforce trained in at least basic or primary palliative care. WHPCA has estimated that approximately 2 million health care workers would be needed to care for a daily census of over 5.6 million patients just at the end of life, including approximately 400,000 palliative care community health workers mainly in low and middle-income countries. This assumes 25.7 million patients receiving an average of 80 days of palliative care. At present we estimate that there are approximately 400,000 health care workers engaged in delivering palliative care globally out of a total of 43.5 million worldwide including 20.7 million nurses and midwives.³⁵ Volunteers also play an important role in hospice and palliative care and bring the community dimension into compassionate care. There are over 1.2 million people volunteering in palliative care around the world. Bridging the gap in access to palliative care will mainly require all the elements in the above public health model but especially ensuring that all health professional receive training in palliative care before graduating from professional schools.

Psychological, social, cultural, and financial barriers

The development of palliative care has been limited by additional human factors. Both hospice and palliative care have come to be associated with the end of life and dying. Psychologically most people fear and avoid anything relating to death. There is often a belief that even acknowledging the possibility that one may die soon is harmful. There is no evidence to support this belief and evidence points to the possibility that palliative care may actually improve survival.^{36 37 38 39 40} However, efforts to engage the public and policy makers on the need for palliative care have met with limited success.

Many cultures have expressly prohibited informing patients of their diagnosis and prognosis when life-threatening. Previously this had been the case in most cultures, but views have been changing in the past several decades to the point where there is now some acceptance of the idea that patients themselves should be given the choice as to whether to receive this information.^{41 42}

Life-threatening illness can have a major impact financially. In many countries effective medical treatment may only be available to those with the financial resources to pay for care. In the United States of America at least half of personal bankruptcies are due to medical bills. While hospice and palliative care have been found to be cost effective in many studies these are mainly in developed countries.

A minimum package of palliative care services has been proposed by the Lancet Commission on Palliative Care & Pain Relief (Pg. 4) that includes human resources, medicines, and equipment. (Fig 31).

Figure 31
What is the Minimum Package of Palliative Care Services?

The Essential Package contains the inputs for safe and effective provision of essential palliative care and pain relief interventions to alleviate physical and psychological symptoms, including the medicines and equipment that can be safely prescribed or administered in a primary care setting. The list of essential medicines in the Essential Package is based on WHO's list of essential medicines,³⁹ and considers the medicines, doses, and administration routes for palliative care for both adults and children.

The Essential Package is designed to be lowest cost by including only off-patent formulations, frugal innovation for needed equipment, and a staffing model based on competencies rather than professions. Tasks often undertaken by specialised medical personnel in high-income countries can be performed by other specialised and general practitioners and nurses or by community health workers empowered with the necessary training and medical supervision to participate effectively in the delivery of palliative care and pain treatment at all levels of care, from the hospital to the home.⁴⁰

With the key exception of morphine, the medicines in the Essential Package are available in most countries even if supply is limited. For morphine, an essential palliative care medicine, assuring safety and accessibility is complex. Ensuring a balance between appropriate medical access to controlled medicines and the prevention of their diversion and non-medical use is crucial, and the Commission not only designed appropriate human resource models but also the strategies to provide the complementary policy and stewardship to expand access to an Essential Package that includes morphine.⁴¹

The health services of the Essential Package must be complemented by interventions for the relief of social and spiritual suffering to preserve the dignity of patients, facilitate access to health interventions, and prevent financial hardship and impoverishment. Yet, these social supports are neither part of the remit of health ministries nor should they be financed from a health budget.

Antipoverty and social development policies, publicly funded safety nets, programmes, and ministries must give special attention to ensure that families do not sacrifice their basic needs in desperate attempts to care for loved ones. These persons with life-limiting or life-threatening health conditions and their families should be mainstreamed into existing social support and social welfare programmes, yet they are often ignored, excluded, or marginalised, preventing them from being effectively integrated into these programmes.

Medicines

- Amitriptyline
- Bisacodyl (Senna)
- Dexamethasone
- Diazepam
- Diphenhydramine (chlorpheniramine, cyclizine, or dimenhydrinate)
- Fluconazole
- Fluoxetine or other selective serotonin-reuptake inhibitors (sertraline and citalopram)
- Furosemide
- Hyoscine butylbromide
- Haloperidol
- Ibuprofen (naproxen, diclofenac, or meloxicam)
- Lactulose (sorbitol or polyethylene glycol)
- Loperamide
- Metaclopramide
- Metronidazole
- Morphine (oral immediate-release and injectable)
- Naloxone parenteral
- Omeprazole
- Ondansetron
- Paracetamol
- Petroleum jelly

Medical equipment

- Pressure-reducing mattress
- Nasogastric drainage or feeding tube
- Urinary catheters
- Opioid lock box
- Flashlight with rechargeable battery (if no access to electricity)
- Adult diapers (or cotton and plastic, if in extreme poverty)
- Oxygen

Human resources (varies by referral, provincial or district hospital, community health center, or home)

- Doctors (specialty and general, depending on level of care)
- Nurses (specialty and general)
- Social workers and counsellors
- Psychiatrist, psychologist, or counsellor (depending on level of care)
- Physical therapist
- Pharmacist
- Community health workers
- Clinical support staff (diagnostic imaging, laboratory technician, nutritionist)
- Non-clinical support staff (administration, cleaning)

Additional detail is provided in the additional online material.

Palliative Care for Special Populations

HIV/AIDS

Until 1996, palliative care was the core clinical response to HIV. The advent of anti-retroviral therapy (ART) has drastically changed HIV mortality, with 770,000 AIDS-related deaths in 2018 compared to 1.7 million in 2004.⁴³ However, ART access is suboptimal in many countries, and mortality rates from advanced AIDS remain high. Eastern and Southern Africa continue to experience the highest mortality (330,000 deaths in 2018). For those who die of AIDS-defining illnesses, the burden of pain symptoms psychological and spiritual concerns remains high.^{44 45} The need for palliative care is changing. Mortality projections to 2060 predict a decline 2016 to 2060 in AIDS-related death,⁴⁶ attributable to the global 90x90x90 strategy. For those who die of AIDS-related illnesses, the traditional roles of palliative care will continue to be needed. Despite evidence of barriers to accessing and delivering palliative care for people living HIV,⁴⁷ it is effective in terms of pain and symptom control, anxiety, insight, and spiritual wellbeing.⁴⁸ However, suboptimal communication,⁴⁹ poor medicine availability,⁵⁰ poor provision of paediatric palliative care,⁵¹ and exclusion of those key populations most affected continue to pose challenges.^{52 53}

With the global focus on testing, treating and maintaining viral suppression, the phenomenon of ageing with HIV presents new roles for palliative care.⁵⁴ The principles of person-centred care remain pertinent in light of high burden of pain, symptoms, spiritual and psychological distress alongside ART,^{55 56} with pain prevalence higher than matched HIV negative controls.⁵⁷ Integration of palliative care principles into outpatient HIV care can improve quality of life, mental health and psychosocial concerns.⁵⁸ As people age with HIV, comorbidity is become increasingly common among PLWH. Since 2011, there has been a 44% increase in infection-unrelated malignancies among HIV-infected people in Europe.⁵⁹ Malignancy survival rates are worse for PLWH.⁶⁰ Non-AIDS cancer is now the leading non-AIDS cause of death for PLWH in the USA, Europe and Australia.⁶¹ By 2030, 28% of PLWH will have at least three non-communicable diseases (largely cardiovascular disease).⁶²

For those who die with HIV, an international comparison found that people living with HIV are more likely than cancer patients to die in hospital.⁶³ In London UK, even when death of a person living with HIV was expected, 61% of died in hospital, and one third had no documented end of life discussion.⁶⁴

Ensuring that all those who die an AIDS-related death can access palliative care remains a global challenge. The new challenge is to ensure that people living with HIV age well with their disease, and that the principles of person-centred holistic palliative care are not lost.

People Affected by Haemorrhagic Fever or Serious Epidemic Infections

Life-threatening infections can cause many types of physical, psychological, social, and spiritual suffering, especially when they occur as epidemics (Table 2). Even geographically limited epidemics, such as the 2014 Ebola epidemic, can cause extreme and multifaceted suffering requiring intensive palliative care, and pandemics such as that due to COVID-19 can generate a need for integrated life-sustaining treatment and palliative care on a massive scale. In all cases, palliative care must be integrated with effective infection control that prioritizes those at greatest risk.

The prevalence, severity, and duration of disease symptoms vary depending on the infection. Physical symptoms of Ebola infection typically include nausea, vomiting, diarrhoea, body aches, fever, and in late stages bleeding, respiratory distress and encephalopathy.⁶⁵ Aggressive control of nausea, vomiting and diarrhoea not only relieves unnecessary suffering but also can protect against volume depletion and electrolyte derangements and hence may improve survival.⁶⁶ It also can reduce contamination of enclosed, shared spaces within Ebola treatment units with virus laden body fluids, hence lessening the risk of transmission to health-care workers.⁶⁷ In some wide-spread life-threatening infections, such as multidrug-resistant tuberculosis, adverse reactions to treatment commonly cause significant suffering and make adherence to treatment difficult.^{68 69} Thus, pain and symptom control are crucial for a variety of reasons.⁷⁰

During epidemics of life-threatening infections, suffering may result not only from the disease but also from the public health response. While quarantining people exposed to an epidemic life-threatening infection and isolating those with active infection may be necessary from a public health perspective, it also may exacerbate psychological and social suffering.^{71 72} Quarantined and isolated patients are at risk for anxiety, depression, and PTSD.⁷³ Wards should be organized to enable patients to communicate with family members/friends at a distance or with mobile phones. Patients should be informed regularly about their condition and prognosis in a way appropriate for their culture and education/literacy level. The poor and socially marginalized may be at highest risk for infection, death, and social suffering with least access to infection control and psychosocial supports.⁷⁴ Thus, infection control and psycho-social-spiritual support should be organized for all affected people, including patients, family members, and those living with income or food insecurity.^{75 76}

Table 2
Common symptoms and forms of distress caused directly by epidemics of severe infections.

	Ebola epidemic	COVID-19 pandemic	Influenza pandemic^a
Pain	X	X	X
Dyspnoea	X	X	X
Nausea/vomiting	X	X	
Diarrhoea	X	X	
Fever	X	X	X
Fatigue/weakness	X	X	X
Delirium	X	X	
Cough	X	X	X
Dizziness	X	X	
Conjunctivitis	X	X	
Oedema	X		
Acute stress reactions	X	X	X
PTSD	ND	X	
Other anxiety disorders	X	X	
Depressive symptoms	ND	X	
Stigmatized/social isolation	X	X	X
Complicated grief	ND	ND	X

Table adapted from:

World Health Organization (WHO). Integrating palliative care & symptom relief into responses to humanitarian emergencies & crises A WHO guide. Geneva: World Health Organization, 2018.

Notes:

- Tan indicates acute symptoms/distress, blue indicates chronic, and grey indicates acute and/or chronic.
- ND = no data
- ^a Hypothetical

Sources:

WHO 2018; Goyal et al. 2020; Suleyman et al. 2020; Guan et al. 2020; Rogers et al. 2020; Vindegaard et al. 2020; Leong et al. 2004; MacNeil et al. 2010; Schieffelin et al. 2014; Dallatomasina et al. 2015; Mollica et al. 2004; Downar and Seccareccia 2010; Reider and Elbert 2013; Caffo and Belaise 2003; West and von Saint André-von Arnim 2014.

People Affected by Serious Injury or Poisoning

Moderate or severe suffering typically associated with chronic life-threatening illness also may occur acutely in association with both life-threatening and non-life-threatening conditions such as injuries, burns, or poisoning. Many patients with serious injuries die so quickly that there is no time to institute palliative care other than pain relief for the patient and bereavement support for the family. However, relieving the acute suffering of the immanently dying and providing bereavement support are crucial humanitarian tasks.⁷⁷ Also, it is estimated that

at least 30% of those who die from injuries or poisoning suffer from pain or other symptoms and survive long enough to benefit from palliative care. It also is estimated that at least twice the number of patients who die of injuries do not die yet need palliative care or pain relief.⁷⁸

In settings where pain medicine does not yet exist as a specialty and is not a major topic in medical education, prevention and relief of pain from trauma, burns, and surgery typically are inadequate. Inadequately controlled acute pain due to trauma or surgery can have serious health consequences including:^{79 80 81}

- Cardiovascular side effects such as arrhythmias, myocardial infarction, congestive heart failure, haemorrhage, and stroke;
- Deep vein thrombosis and pulmonary embolism;
- Atelectasis and pneumonia;
- Hyper-catabolic state and tissue wasting;
- Compromised immune function and increased risk of infection;
- Development of persistent chronic pain (especially common after limb and breast amputations);
- Mental health problems including anxiety, depression, PTSD, impaired sleep, and demoralization.

In these settings, clinicians trained in palliative care should intervene by training colleagues in symptom control, by providing direct symptom relief, or both (WHO 2018). Many countries also lack rehabilitation medicine specialists and programs to care for people with non-life-threatening but serious disabilities such as paraplegia or quadriplegia or those due to brain injuries or congenital anomalies. Palliative care can help to fill this void as well. Planning and implementing palliative care services should be based on assessment of the types and extent of inadequately prevented or relieved physical, psychological, social or spiritual suffering of adults and children.⁸²

Palliative Care for Tuberculosis

Awareness on the need to deliver palliative care for multidrug-resistant TB is relatively new. TB is the second leading cause of death in adults from an infectious disease worldwide after HIV. In 2018, about 10.0 million people fell ill with TB, with an estimated 32% and 11% corresponding to women and children respectively. Mortality is one of the major indicators of the burden of TB and the state of its control in the world. An estimated 1.45 million deaths were attributed to TB, including 251,000 deaths among people with HIV).

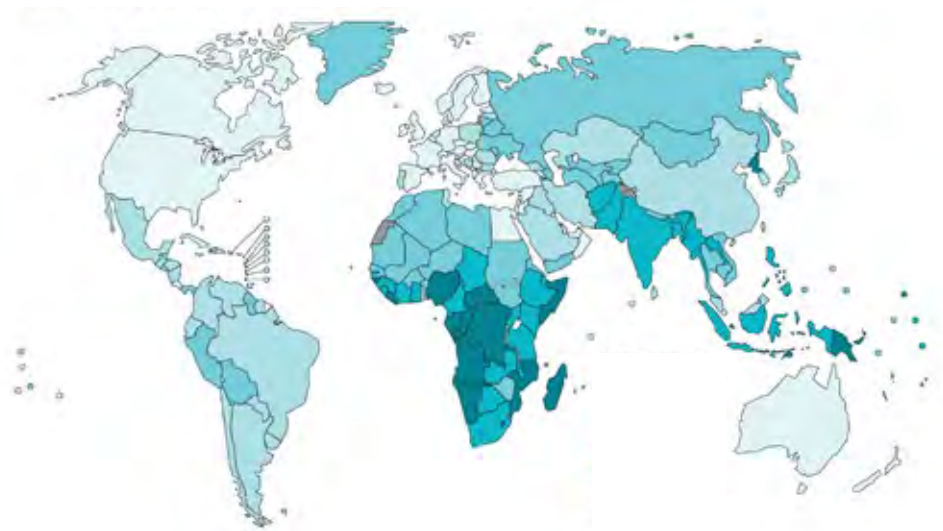
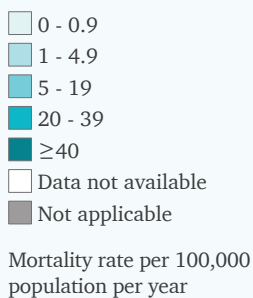
Furthermore, in 2018 there were 484,000 estimated cases of MDR or rifampicin-resistant TB (MDR/RR-TB), those in need of treatment with second-line TB medicines. The latest global TB report also showed a low treatment success rate for MDR/RR-TB,⁸³ at 56% globally, which reflects high rates of mortality, loss to follow-up or no evaluation of treatment outcome. Poor treatment outcomes reflect major suffering among those in whom treatment has failed or in whom adherence to treatment has shown to be too difficult to maintain.

WHO's End TB strategy has a target to reduce the global TB incidence by 80% and TB deaths by 90% and to eliminate the catastrophic costs for TB affected households rate by 2030. Between 1990 and 2010, TB mortality rates fell by just

over a third and the 2030 target is expected to be achieved both at the global level as well as in all regions of the world on the assumption that new tools are developed by 2025. These positive developments nonetheless mask the harsh reality that most of the 4000 or so TB deaths which occur each day in the world are preventable.

Without early detection, rapid diagnosis and adequate treatment and care End TB target won't be achieved. For patients with TB/HIV the risk of dying is higher, especially if access to anti-retroviral treatment is low. Patients with multi-drug-resistant TB (MDR-TB) have a higher risk of dying even in countries where treatment is available. Reports of cases with both HIV and extensively drug-resistant TB (XDR-TB) have been characterized by very high mortality. TB disease can damage the lungs and other organs irreversibly and death may ensue from complications such as respiratory failure or haemoptysis as a late sequela of disease, even if the initial outcome of treatment is favourable. Palliative care and symptomatic relief in patients with severely compromised lung function are important considerations in the care of TB patients.

Figure 32
World Map showing global TB mortality rates for HIV-Negative people (WHO Global TB Report 2019)



Summary and conclusions

Palliative care is still relatively new to national health systems, particularly in low-and middle-income countries (LMICs). A public health approach is needed to foster the development of palliative care services and to overcome existing barriers to palliative care development. Significant barriers exist in the lack of clear policies establishing palliative care, lack of educational programmes to teach palliative care, lack of research on palliative care especially in LMICs, lack of essential medications needed to deliver palliative care, and lack of organized programmes to deliver palliative care. All these barriers can be overcome. Existing resources are available that can be adapted to individual countries to fill these gaps. What is needed is the will to do so and to recognize that lack of palliative care is a problem that leads to unnecessary suffering for the people who are among the most vulnerable in a society.

How are palliative care services developing worldwide to address the unmet need for care?

David Clark, Carlos Centeno, David Clelland, Eduardo Garralda, Jesús López-Fidalgo, Julia Downing, Cherian Varghese, Stephen Connor

Responding to the enormous unmet need for palliative care has been very challenging. In the over 50 years since the opening of St. Christopher's Hospice in the United Kingdom there has been a slow but steady growth in programmes that serve the needs of those with life-threatening illness. There are now approximately 25,000 hospice or palliative care service units worldwide (see Pg 57). Parallel to the development of services, we have seen in Chapter 3 the need for access to palliative care education, and at the same time access to essential palliative care medications.

One of the ways to monitor the growth of palliative care worldwide has been the development of a system of mapping palliative care development on a country-by-country basis. This work was first published in 2006 by Wright, Lynch, & Clark. They measured palliative care development in all countries of the world and classified each using a four-part typology depicting levels of hospice-palliative care development across the globe: no known hospice-palliative care activity (group 1 countries); capacity building activity (group 2 countries); localised hospice-palliative care provision (group 3 countries); and countries where hospice-palliative care services were reaching a measure of integration with the mainstream healthcare system (group 4 countries).

From this early work it was clear that the rankings would benefit from refinement and the method of categorisation could also be made more robust. In order to update the original findings and also address the definitional and methodological concerns, the 2006 mapping exercise was repeated in 2011, with some new criteria. Changes were made to the criteria for level of palliative care development in groups 3 and 4 and each was sub-divided to produce two additional levels of categorisation (groups 3a and 3b/4a and 4b). The results from this study (Lynch, Connor, & Clark, 2013)⁸⁴ were used in the first edition of this Atlas. Now, and following further methodological refinement, the findings of a third study, based on data from 2017 (Bauer et al, 2019; Clark et al, 2020)^{85 86} are used in this chapter to show changes and improvement in palliative care capacity to deliver services worldwide.⁸⁷

In addition to the mapping of palliative care generally around the world we also include in this chapter a report on the levels of paediatric palliative care development worldwide. Paediatric palliative care development has run parallel to adult palliative care but at a much lesser rate. We report on levels of paediatric palliative care development using the new six-level schema, also based on results from 2017, to provide a measure of the progress that still needs to be made and the unique challenges to bringing palliative care to children worldwide.⁸⁸

An additional way of monitoring the availability of palliative care is based on the use of morphine and other opioids for pain relief. Data published by the International Narcotics Control Board (INCB) reports the amount of opioid use annually. This data has been aggregated by country by the Walther Centre in Global Palliative Care, based at Indiana University (USA). In Chapter 3 we reported on morphine and opioid usage as an indicator of palliative care development (See Figures 26 & 27). This same measure has been proposed by WHO as a country level indicator for progress on treatment of non-communicable disease. There are also regional studies available from Europe (2019),⁸⁹ Africa (2017),⁹⁰ Eastern Mediterranean Countries (2017),⁹¹ and Latin America (2013).⁹² These mapping surveys offer complementary information country by country useful in comparing type of services, education, use of medicines and policies. Those works have been produced by the ATLANTES Global Palliative Care Observatory of the University of Navarra in close collaboration with the global and regional organisations.

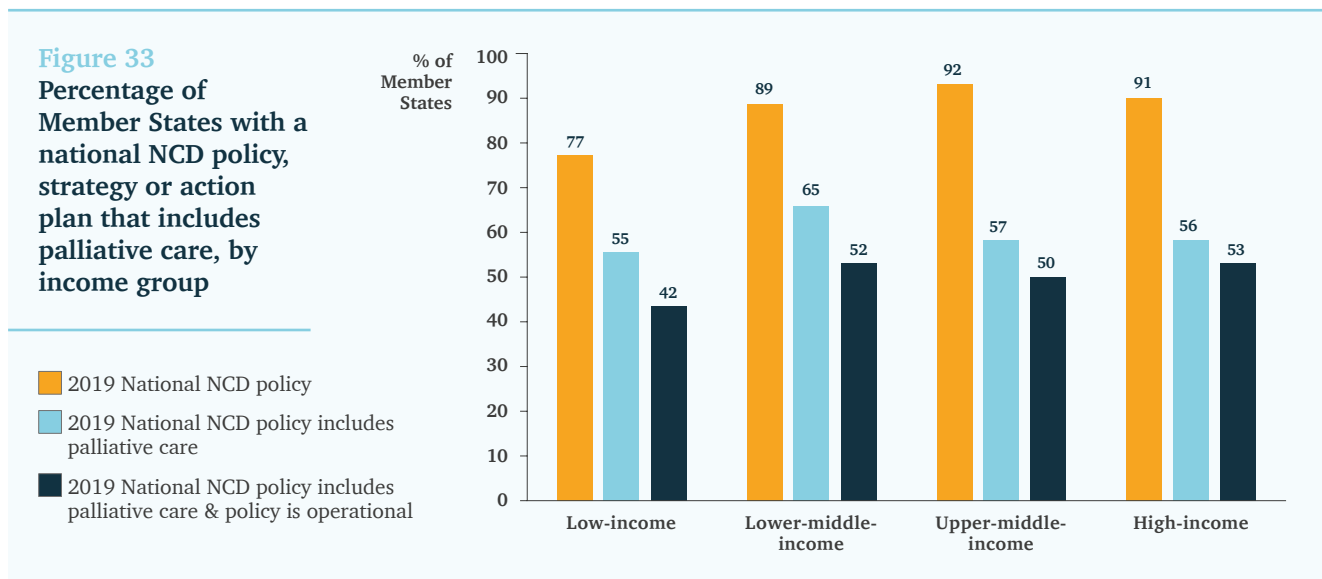
Finally, the WHO has included measures of palliative care policy development in regular reports from UN member states, as part of its assessment of progress in addressing the growth of non-communicable diseases.

Results of palliative care findings from the WHO Country Capacity Survey for the Prevention and Control of Noncommunicable Diseases (2019)⁹³

The WHO conducts a bi-annual survey to assess all member states' capacity for the prevention and control of noncommunicable diseases (NCDs). The 2019 survey included questions about the level of palliative care policy and development in 194 WHO member states. Based on survey responses and evidence provided it produced the following results:

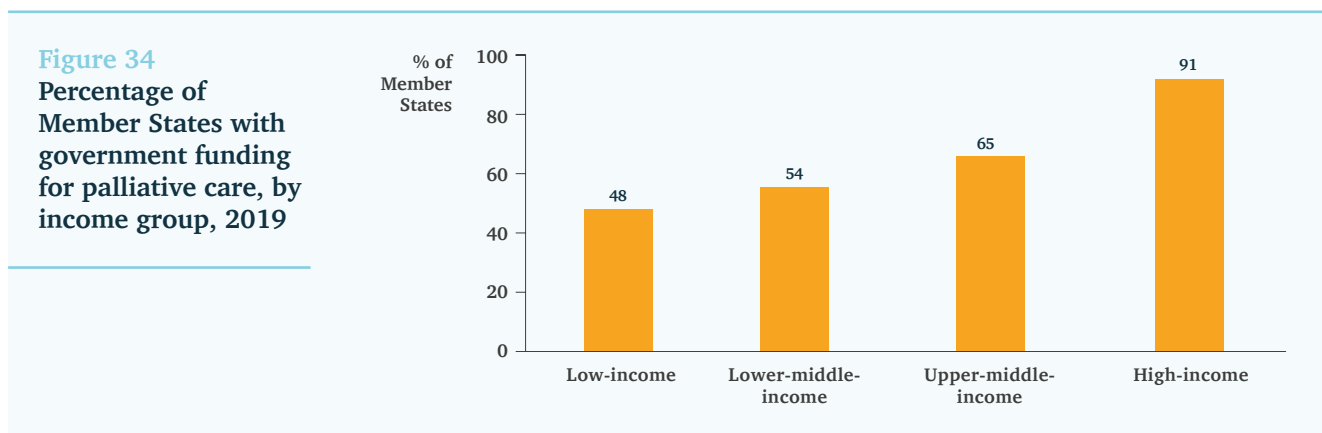
- The integration of palliative care in response to NCDs (Figure 33)

In 2019, only 50% of countries globally report having palliative care within their national NCD policy that is operational, with little variation in the availability across income groups.



- Allocation of government funding for palliative care (Figure 34)

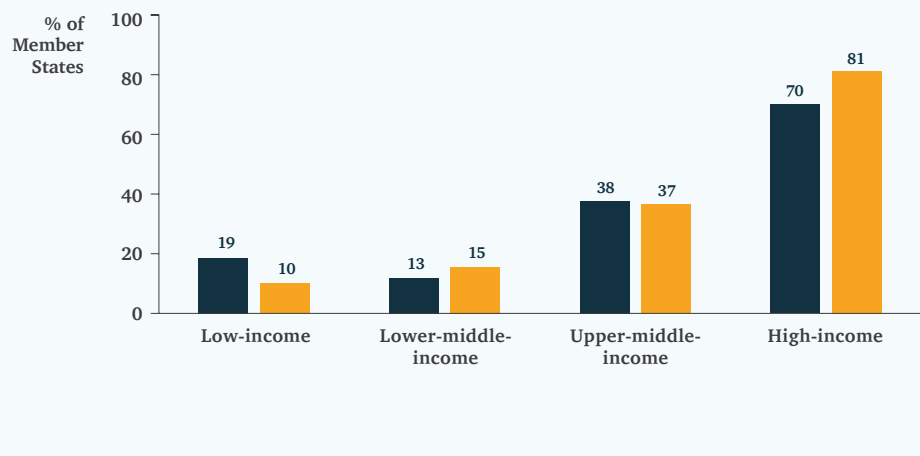
Over two-thirds (68%) of countries globally have some dedicated funding for palliative care. More countries in high-income countries (HICs) (91%) allocated funds than in low-income countries (48%). (Figure 34).



- Availability of palliative care services

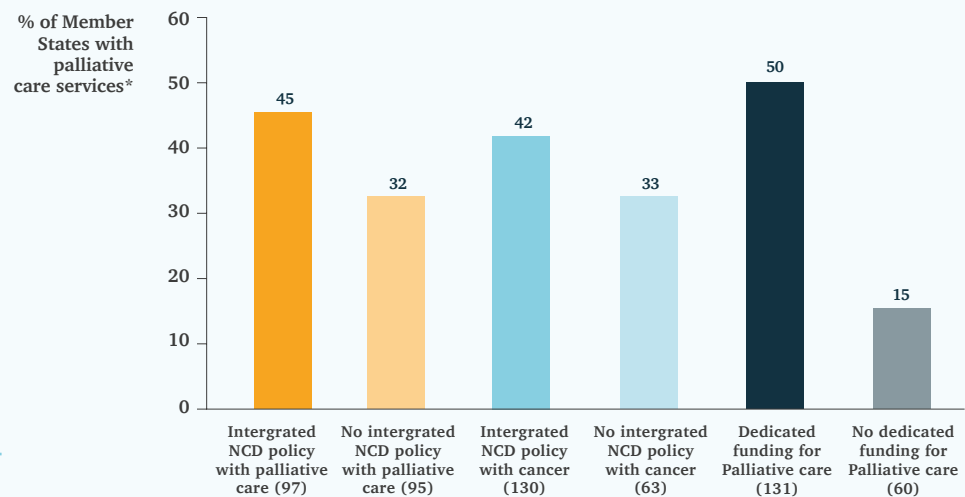
Availability to palliative care services remains limited for patients with NCDs globally, with only 39% of countries reporting general availability (reaching at least 50% of patients in need) in primary health care and 40% in community- or home-based care. Palliative care is far more widely available to patients in high-income countries (81% for home-based or community-care; 70% for primary health care) than in upper-middle-income (37%; 38%), lower-middle-income (15%; 13%) and low-income countries (10%; 19%). (Fig 35)

Figure 35
Percentage of Member States providing palliative care for NCD patients through primary health care, home-based care or community-care, by income group, 2019



Palliative care is more likely to be available in countries where operational NCD policy integrates palliative care (45%) or cancer (42%) than in those without palliative care (32%) or cancer (33%) within their NCD policy. Correspondingly, countries that allocate funding for palliative care are more likely to have these services available than those without dedicated funding. Palliative care is generally available to patients in need in primary health care facilities in 50% of countries where funding is specifically allocated as compared to 15% of countries where there is no dedicated funding for palliative care. (Figure 36).

Figure 36
Percentage of Member States reporting general availability of palliative care (reaching at least 50% of patients in need) in primary health care, by integrated NCD policy and funding availability, 2019

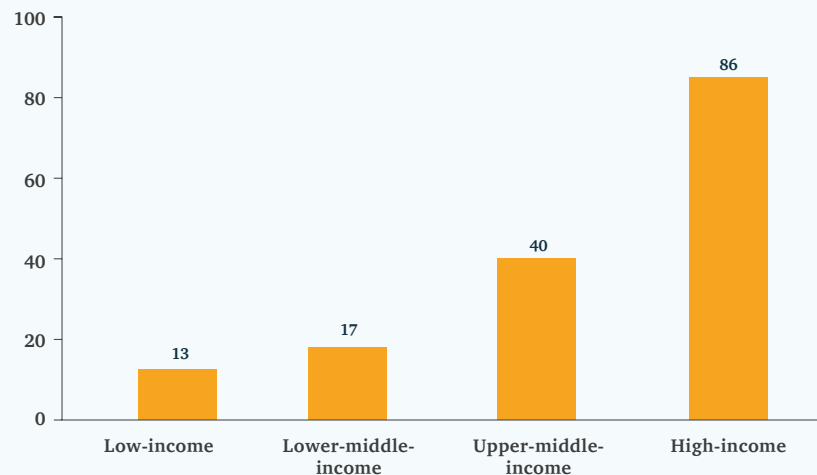


*Palliative care services in primary health care reaching at least 50% of patients in need; numbers in brackets indicate denominators for each group, excluding countries with unknown status of funding or where existence of integrated NCD policy was unknown.

- Access to opioid pain relief

Opioid pain relief for palliative care remains sparsely available in LMICs. Oral morphine is reported as generally available in 44% of countries worldwide, with a large gap between income groups. (Figure 37).

Figure 37
Percentage of Member States reporting general availability of oral morphine (available in >50% of pharmacies) in public primary care facilities, by income group, 2019.



Dedicated funding is also crucial in improving accessibility to opioids. Oral morphine is generally available in more than 57% of countries where there is allocated funding for palliative care. The availability falls to 15% in countries without dedicated funding for palliative care.

Conclusion

There is a substantial gap in funding and availability of palliative care for NCDs amongst country groups by income. There is an urgent need to scale up palliative care services for NCDs in LMICs through policies, resources, services in primary care and access to opioids such as morphine.

These results are generally consistent with the results of the next section on mapping levels of palliative care development.

Mapping levels of palliative care development: a global update 2017⁹⁴

We report here on a global programme of work that has been monitoring country level development in palliative care for more than a decade, beginning in 2006,⁹⁵ followed up in 2011⁹⁶ and now updated for 2017. These studies have contributed significantly to advocacy, planning and monitoring of palliative care worldwide. In 2014, the second study formed a key aspect of the evidence base for the 67th World Health Assembly (WHA) Resolution on Palliative Care, which was supported by all member states. One goal of the research has been to improve the quality of study design at each iteration, taking account of published feedback^{97 98} whilst at the same time presenting an unfolding analysis of global palliative care development over time.

The aims of the third study, based on data from 2017, were threefold. First, to allocate each jurisdiction to one of six categories of palliative care development (Figures 34-40) by the use of an online survey of in-country experts who were asked to provide data on palliative care in their country. Second, to track category changes over time by comparing results from the two earlier studies with the data from 2017. Third, to improve the under-lying methodology by the creation and use of 10 designated palliative care development indicators and an algorithm for classification, along with further statistical testing.

Categorisation of palliative care development 2017, N = 198

Group 1 countries:

No known hospice-palliative care activity: Although it was not possible to identify any palliative care activity in this group of countries, it is acknowledged that there may be instances where, despite best efforts, current work has been unrecognised.

Table 3
Countries with no known hospice palliative care activity (Level 1)

Category 1: No known palliative care activity 47 countries (24%); 235 million people (3.1 % of world population)	Africa	Cape Verde, Central African Republic, Chad, Comoros, Congo (Republic), Guinea-Bissau*, Lesotho, Mali, Seychelles, South Sudan
	Americas	Antigua & Barbuda, Cuba, Dominica*, Grenada*, Guyana, Saint Lucia, St Kitts & Nevis*, St Vincent & the Grenadines*, Suriname*
	Eastern Mediterranean	Djibouti, Iraq, Somalia, Somaliland, Syria*, Yemen
	Europe	Andorra, Kosovo*, Monaco, Montenegro, San Marino*, Turkmenistan, Vatican City
	South-East Asia	Bhutan, Maldives*, North Korea, Timor l'Este
	Western Pacific	Brunei, Kiribati, Laos, Marshall Islands, Micronesia*, Nauru*, Palau*, Solomon Islands*, Tonga, Tuvalu*, Vanuatu*

Note: *denotes countries placed in Category 1 because no contacts for survey were identified

Group 2 countries:

Capacity building activity: A country in this category shows evidence of wide-ranging initiatives designed to create the organisational, workforce, and policy capacity for the development of palliative care services, although no service has been established yet. Developmental activities include attendance at, or organisation of, key conferences, personnel undertaking external training in palliative care, lobbying of policy makers and Ministries of Health and emerging plans for service development.

Table 4
Countries with capacity building activity (Level 2)

Category 2: Capacity-building palliative care activity 13 countries (7%); 126 million people (1.7 % of world population)	Africa	Angola, Burkina Faso, Burundi, Equatorial Guinea, Eritrea, Gabon, Liberia, Sao Tome e Principe
	Americas	Bahamas, Haiti
	Eastern Mediterranean	United Arab Emirates
	Europe	Uzbekistan
	South-East Asia	-
	Western Pacific	Samoa

Group 3 countries:

3a) Isolated palliative care provision: A country in this category is characterised by the development of palliative care activism that is still patchy in scope and not well supported; sources of funding that are often heavily donor dependent; limited availability of morphine; and a small number of palliative care services that are limited in relation to the size of the population.

3b) Generalized palliative care provision: A country in this category is characterised by the development of palliative care activism in several locations with the growth of local support in those areas; multiple sources of funding; the availability of morphine; several hospice palliative care services from a range of providers; and the provision of some training and education initiatives by the hospice and palliative care organisations.

Table 5
Countries with isolated provision of palliative care (Level 3a)

Category 3a: Isolated palliative care provision 65 countries (33%); 3,597 million people (47.7% of world population)	Africa	Algeria, Benin, Botswana, Cameroon, Congo (DR), Ethiopia, Ghana, Guinea, Madagascar, Mauritania, Mauritius, Mozambique, Namibia, Niger, Nigeria, Rwanda, Senegal, Sierra Leone, Tanzania, Togo
	Americas	Bolivia, Dominican Republic, Ecuador, Guatemala, Honduras, Jamaica, Nicaragua, Paraguay, Peru, Trinidad & Tobago, Venezuela
	Eastern Mediterranean	Afghanistan, Bahrain, Egypt, Iran, Kuwait, Lebanon, Libya, Morocco, Pakistan, Palestine, Sudan, Tunisia
	Europe	Armenia, Azerbaijan, Bosnia & Herzegovina, Croatia, Estonia, Greece, Kyrgyzstan, Moldova, Tajikistan, Turkey
	South-East Asia	Bangladesh, India, Indonesia, Myanmar, Nepal, Sri Lanka
	Western Pacific	Cambodia, Fiji, Malaysia, Papua New Guinea, Philippines, Vietnam

Table 6
Countries with generalized provision of palliative care (Level 3b)

Category 3b: Generalised palliative care provision 22 countries (11%); 426 million people (5.7 % of world population)	Africa	Gambia, Kenya, Zambia
	Americas	Belize, Brazil, Colombia, El Salvador, Panama
	Eastern Mediterranean	Jordan, Oman, Qatar, Saudi Arabia
	Europe	Albania, Belarus, Bulgaria, Cyprus, Finland, Luxembourg, Macedonia, Malta, Serbia, Slovenia,
	South-East Asia	-
	Western Pacific	-

Group 4 countries:

4a) Countries where hospice-palliative care services are at a stage of preliminary integration into mainstream service provision: A country in this category is characterised by the development of a critical mass of palliative care activism in a number of locations; a variety of palliative care providers and types of services; awareness of palliative care on the part of health professionals and local communities; a palliative care strategy that has been implemented and is regularly evaluated; the availability of morphine and some other strong pain-relieving drugs; some impact of palliative care on policy; the provision of a substantial number of training and education initiatives by a range of organisations; and the existence of a national palliative care association.

4b) Countries where hospice-palliative care services are at a stage of advanced integration into mainstream service provision: A country in this category is characterised by the development of a critical mass of palliative care activism in a wide range of locations; comprehensive provision of all types of palliative care by multiple service providers; broad awareness of palliative care on the part of health professionals, local communities, and society in general; a palliative care strategy that has been implemented and is regularly updated; unrestricted availability of morphine and most strong pain-relieving drugs; substantial impact of palliative care on policy; the existence of palliative care guidelines; the existence of recognised education Centres and academic links with universities with evidence of integration of palliative care into relevant curricula; and the existence of a national palliative care association that has achieved significant impact.

Table 7
Countries with preliminary health system integration (Level 4a)

Category 4a: Palliative care at preliminary stage of integration 21 countries (11%); 2,083 million people (27.6 % of world population)	Africa	Côte d'Ivoire, South Africa, Uganda, Zimbabwe
	America	Argentina, Chile, Mexico, Uruguay
	Eastern Mediterranean	-
	Europe	Austria, Czech Republic, Georgia, Hungary, Kazakhstan, Latvia, Russia, Slovakia, Switzerland, Ukraine
	South-East Asia	Thailand
	Western Pacific	China, Singapore

Table 8
Countries with advanced health system integration (Level 4b)

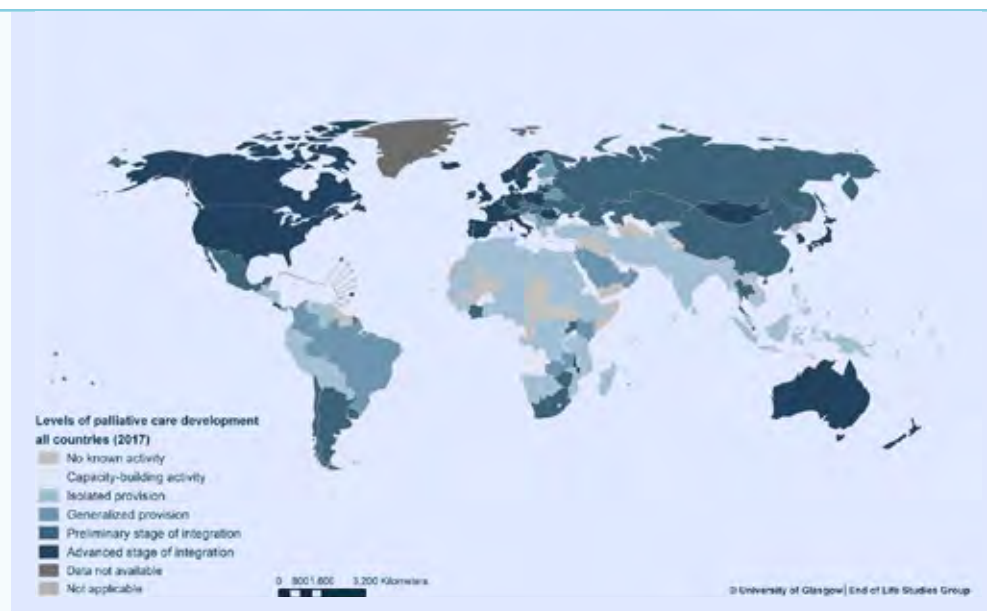
Category 4b: Palliative care at advanced stage of integration 30 countries (15%); 1,074 million people (14.2 % of world population)	Africa	Malawi, Swaziland
	America	Barbados, Canada, Costa Rica, USA
	Eastern Mediterranean	-
	Europe	Belgium, Denmark, France, Germany, Iceland, Ireland, Israel, Italy, Liechtenstein, Lithuania, Mongolia, Netherlands, Norway, Poland, Portugal, Romania, Spain, Sweden, United Kingdom
	South-East Asia	-
	Western Pacific	Australia, Japan, New Zealand, South Korea

Summary and conclusions

Palliative care is gaining ground globally and is endorsed in high-level policy commitments, but service provision, supporting policies, education, and funding are incommensurate with rapidly growing needs. Numbers (percentages) of countries in each development category were as follows: 1) no known palliative care activity, 47 (24%); 2) capacity-building, 13 (7%); 3a) isolated provision, 65 (33%); 3b) generalized provision, 22 (11%); 4a) preliminary integration into mainstream provision, 21 (11%); 4b) advanced integration, 30 (15%). Development levels were significantly associated with World Bank Income groups WBIG ($r_s=0.4785$), Universal Health Coverage ($r_s=0.5558$), and Human Development Index ($r_s=0.5426$) with $P < 0.001$. Net improvement between 2006 and 2017 saw 32 fewer countries in Categories 1/2, 16 more countries in 3a/3b, and 17 more countries in 4a/4b.

Palliative care at the highest level of provision is available for only 14% of the global population and is concentrated in European countries. An 87% global increase in serious health-related suffering amenable to palliative care interventions is predicted by 2060. With an increasing need, palliative care is not reaching the levels required by at least half of the global population.

Figure 38
Levels of palliative care development – all countries (2017)



Paediatric Palliative Care Development

Hospice programmes for children began in the United Kingdom and the United States at similar times in the 1970s. Since then, paediatric palliative care has been recognised in many countries as a distinct specialty. Accessibility to paediatric palliative care varies widely across the world, with wide variations such that there are gaps and unmet needs worldwide. Often the need for children's palliative care (CPC) is underestimated and it is important to recognise that the provision of palliative care to children with life-limiting and life-threatening illnesses differs from that of adults, and the development and provision of paediatric palliative care often lags behind that for adults. The need for paediatric palliative care varies between regions, countries and low-middle-high income groups. The Lancet Commission on relieving the access abyss to pain and palliative care reported that in low-income countries, childhood deaths account for >30% of all deaths associated with Serious Health-related Suffering (SHS), compared to <1% in high income countries (Knaul et al 2017).⁹⁹

Separate studies on paediatric palliative care development that parallel the mapping of adult palliative care have been published.^{100 101} These reviews identified disparities between regions e.g. North America and Europe, when compare with Africa, Asia and Latin America. These disparities, echoed in this publication, were also noted in the first edition of the Global Atlas of palliative care at the end of life,¹⁰² in the directory of paediatric palliative care services globally held by the International Children's Palliative Care Network (ICPCN),¹⁰³ and in the APCA Atlas of Palliative Care in Africa,¹⁰⁴ the Atlas of Palliative Care in Latin America,¹⁰⁵ and the European Atlas.¹⁰⁶

Apart from the ICPCN's global directory of paediatric palliative care services, there has not been a central repository to track progress in paediatric palliative care, and no accepted indicators for paediatric palliative care, or way of measuring service provision, capacity development etc. However, there is a need to understand where countries are in the evolution of service provision in order to plan ongoing development. Provision is an ever-changing concept. Results from of six levels of paediatric palliative care development are noted in figure 39 below.

Numbers of patients receiving palliative care and palliative care service providers

The number of patients receiving palliative care worldwide is unknown. There are a few countries that publish data on number of patients receiving care including the United States where numbers of patients enrolled in the Medicare Hospice Benefit are tracked and a registry in Australia. Additionally, some countries produce estimates like the UK, but there is no global registry. We have developed a method for estimating those receiving palliative care by country using the number of service providers (Connor et al, In-press).¹⁰⁷

There are differences in the average number of hospice or palliative care patients based on WBIG. Generally, a service has the resources to see more patients the higher the income group. Based on the results of the survey used in mapping levels of palliative care development we have estimated that in 2017 there were approximately 25,000 services delivering hospice or palliative care worldwide. The average service was found to have the following number of patients under service in 2017 based on WBIG:

Low Income	133
Lower Middle	187
Upper Middle	297
High Income	324

Using these averages against the number of services we estimate that 7 million patients received palliative care in 2017.

Table 10
Estimated Patients Receiving Palliative Care Globally by Region and Income Group

WHO Region	N	%
AFRO	231,689	3
EMRO	23,569	<1
EURO	2,943,900	43
PAHO	2,202,152	31
SEARO	187,214	3
WPRO	1,415,822	20.0
Totals	7,004,347	100.0

World Bank Income Group

High Income	4,812,380	69
Upper Middle	1,935,548	27
Lower Middle	227,009	3
Low Income	29,410	1
Totals	7,004,347	100.0

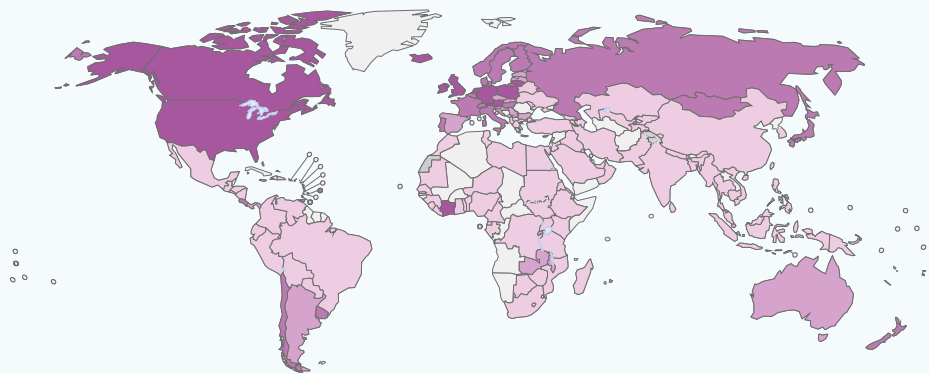
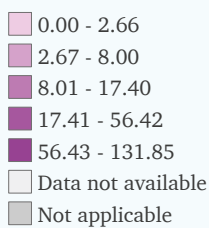
Table 11
Estimated Services Delivering Palliative Care Globally by Region and Income Group

WHO Region	N	%
AFRO	1085	4
EMRO	78	<1
EURO	9844	39
PAHO	8605	34
SEARO	800	3
WPRO	4987	19
Totals	25,399	100

World Bank Income Group

High Income	17602	69
Upper Middle	6450	25
Lower Middle	1114	5
Low Income	233	1
Totals	25,399	100

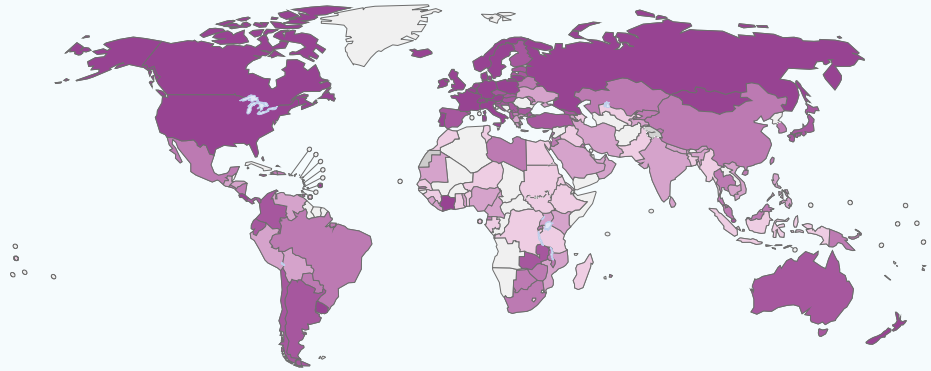
Figure 40
Services/providers to base population (per 1M population) 2017



Rates of number of services delivering Palliative Care
 Number of services (per '000'000 pop.)

Figure 41
Estimated number of patients receiving palliative care (per 1M population) 2017

- 0.00 - 23.32
- 23.33 - 142.72
- 142.73 - 559.20
- 559.21 - 2,932.84
- 2,932.85 - 42,675.32
- Data not available
- Not applicable



Rates of number of services receiving Palliative Care
 Number of patients (per '000'000 pop.)

5

What are the existing models of palliative care development in different resource settings?



“Go around and see what is being done and then see how your own circumstances can produce another version; there is need for diversity in this field.”

Dame Cicely Saunders, Founder
St. Christopher's Hospice

In this chapter we will highlight some examples of how hospice and palliative care services are delivered throughout all regions of the world. We are holding up some of the model programmes that have developed in different cultural contexts, often with close community involvement. There are examples of programmes from every region of the world. Each story includes a description of the model, levels of support from the local health care system, innovative aspects, and descriptions of sustainability. Together these programmes are examples of where hospice and palliative care has found a way to be successful in diverse settings and often with limited resources.

We also include a section with voices from people living with palliative care needs. These individuals teach us what is most important about palliative care what is needed to ensure dignity and quality of life in different cultural and diverse settings.

**SOUTH EAST
ASIA REGION****Community based care for older people living with life-limiting and chronic illness in Korail, the largest informal settlement in Bangladesh****Situational Context**

There are few examples of targeted palliative care programmes in informal communities in developing countries which empower them to have choice and control, and to support communities to help each other. This project aimed to support the complex needs of impoverished older people affected by life-limiting illness living in Korail, the largest such settlement in Dhaka. The population of informal settlements in Dhaka increased threefold from 718,143 in some 2156 and clusters in 1991, to a population of 2,227,754 across 13,938 clusters in 2014.

Description of the model

Centre for Palliative Care at the Bangabandhu Sheikh Mujib Medical University (BSMMU), Dhaka, Bangladesh (implementing partner); The Bangladesh Medical Association, The Ministry of Health and local community NGOs, the local activist group; engagement with seven non-government organisations active in health care issues. The project closely engaged with these NGOs, particularly around patient referral and embedding compassionate care and palliative care principles into their work.

The primary implementing partner provided medical and nursing support as a part of the university's service to deliver home care visits to Korail. These services included free inpatient care and essential meds including oral morphine in line with university protocol on essential medicines, vision services including free eyeglasses and medicines, and ongoing research support. Delivery of home-based care and distribution of information and ideas amongst the community was critical to increasing understanding and raising awareness around the concept of 'compassionate communities' and the sustainability of this palliative care model.

Level of support from the existing health system**Innovations**

- **Use of Palliative Care Assistants (PCAs) to support compassionate community building**

The project engaged eight Palliative Care Assistants who were identified and trained from the community itself to work with and provide care to older community members. The PCAs worked out of a palliative care hub which served as a community focal point for PCAs and activists and to train the community leadership.

- **Development of a local activist group of older persons**

An older people's activist group was developed based on existing models of older people's groups that functioned well already within the community. The group included community leaders and provided strategies for community members to support one another's physical, psychosocial and spiritual needs.

Sustainability

The development of this project focussed on lessons learned from the Kerala community palliative care model in South India as well as the lessons from Island Hospice, Zimbabwe. Both of which have developed sustainable models of community owned and led palliative care.

The project design was based on community members investing in their own development through social enterprise approaches with skilled support. While those living with life-limiting illness may have reduced capacity to give back, the project closely supported the engagement of family members and carers who have indirectly benefited from the project and who understand its importance.

Community members also engaged in the development of a full sustainability plan within the first six months with a comprehensive exit strategy. At the local level, this plan focussed on building the leadership of the community CBO leaders in the Korail both to lead and participate in the project.



Case study: Indonesia

Situational Context

Established in 2006, Rachel House is the first home-based paediatric palliative care service in Indonesia, with a vision that “no child should ever live or die in pain”. In Indonesia, close to 700,000 children are suffering with serious or life-limiting illnesses and less than one per cent of them have access to palliative care*. Palliative care and home care are not covered under Indonesia’s universal health coverage (UHC) program.

Description of the model

Rachel House’s free, nurse-led service provides pain and symptom management and psychosocial care for children living with life-threatening illnesses. It aims to create an ecosystem of patient-centred care that enables children of all ages to live and die comfortably at home. The nurses are empowered to plan and deliver palliative care, in consultation with referring doctors, supported by a panel of international experts and a network of local community health workers.

Level of support from the existing health system

Rachel House works closely with the health services at all levels of the health system, from primary care clinics to tertiary hospitals. This close relationship is key to the adoption of palliative care and the use of pain medications in several major hospitals throughout Jakarta (where Rachel House works). It is hoped that this builds the momentum and the impetus for the Indonesian government to include palliative care in its UHC program.

Innovations

Collaboration has been the modus operandi for Rachel House, as the pioneering palliative care service in Indonesia with limited resources. Staffed with only nurses to provide care for the vast population with little or no access to care at the end of life, Rachel House decides to focus on training to empower all with the basic skills to care. In 12 years, the training has reached 6000 healthcare professionals and 2500 community volunteers.

Sustainability

A sustainable model is developed by leveraging international expertise to build the knowledge and skills of healthcare professionals and volunteers in Indonesia. This team of palliative care trained doctors and nurses will continue to disseminate the knowledge to all within the health system and the academia to ensure access to all. Eventually, Rachel House plans to develop a centre of excellence in home-based paediatric palliative care to replicate its service and model throughout Indonesia.



Rachel House's nurse providing the much-needed care and symptom control for children living with life-threatening illnesses from the marginalised communities.

(Photo credit: Ryner St John, NGO Photographers Alliance)



Rachel House's trained community health workers provide support for the children and families in their neighbourhood.

(Photo credit: Kartika Kurniasari)

AFRICAN REGION

Island Hospice and Healthcare Zimbabwe

Situation context: Taking PC to people in need

Island was the first hospice in Africa, providing Palliative Care (PC) services in Zimbabwe since 1979. Whilst conducting clinics at the Chikwaka Rural Health Centre in 2008, the team observed that patients were failing to attend. The Community Home Based Care Service (CHBC) advised that many patients lived in hard-to-reach areas, were too ill, and could only make it to the nearest road. As a result, days were set aside to serve patients from those hard-to-reach areas in Goromonzi District.

Description of Model:

An Island vehicle is parked on the side of the road, at a predetermined time and location, close to clusters of patients in need of PC services. Island staff work with trained CHBCs who refer and escort the patients to the designated point. The clinic provides assessment and medication & sundries as well as medical equipment to patients.

Level of support from existing HC systems:

The model is supported by an established network of collaborators, including medical professionals at the district hospitals and clinics, through to the discharge plan in which community health workers are involved. Island staff provide PC training to community health workers. CHBCs are the link between patients and families in need of PC and Island and this forms an essential entry point of patient referral to the mobile road-side clinic.

Innovation:

The clinic sees up to 100 patients per month, thus extending access to PC to the most needy and hard-to-reach population. Patients now receive service and access medical equipment at their nearest access point. Patients and families who need psychosocial support are referred to the Social Worker. Patient home care education is provided. The clinic has managed to dispel misconceptions about PC, including concerns about morphine in pain management.

Sustainability:

Island mobile roadside clinic encourages the involvement of the community through community leaders, health centre committees and other, local stakeholders providing service in the community. Island also works with public health facilities in the area. For patients facing end-of-life, this model provides access to much-needed, yet often out of reach palliative care service.



A PC Nurse consultation



Nurse dispensing medication to a patient

EUROPEAN REGION

First Moscow Hospice

Development background

Palliative care in Russia began with the opening of hospices for cancer patients in St. Petersburg and Moscow in 1990-s thanks to the initiative of Polish journalist Viktor Zorza. In 2011, in Russian law, palliative care was allocated as a separate type of medical care, which is guaranteed to citizens of the country free of charge. At present, about 1 million 800 thousand people with incurable progressive diseases need palliative care in Russia. Since 2011 more than 15000 beds have been opened in the country and about 800 visiting patronage services have been created.

Programme model

Hospice is a healthcare institution designed to provide specialized medical, social, psychological, spiritual and legal assistance to incurable cancer patients and their families both during the period of illness and after the loss of loved ones.

Hospice staff provide patients with ongoing care; relieve pain and other burdening symptoms, which requires not only drug therapy, but also the professional ability to switch the patient, distract him, provide comfort – physical and psychological. The requirements for hospice staff are very high.

The hospice includes an on-site patronage service for palliative care, which works 7 days a week for 12 hours a day. On average, a field service makes 10 medical, 20 nursing, and 10 social workers trips. About 5 volunteers are engaged to home service weekly. Under the supervision of on-site service, there are about 500 people at once. The frequency of staff visits to the hospice depends on the individual needs of the patient, the severity of his condition and the presence of the caregiver. If in-home care is impossible, the patient is hospitalized in a hospice.

The round-the-clock treatment department is designed for 30 patients; the doctor and nurses are on duty 24 hours to provide patient monitoring and a treatment plan section, including pain therapy and other serious manifestations of the disease. During the year, the department serves more than 700 people with cancer and non-cancer disease. Mortality in the ward is about 78%, and the average days spend in bed is 13 days.

Support units and services include laundry, kitchen, administrative part, volunteer room, mini-zoo, chapel and garden. Since March 2017, the First Moscow Hospice named after Millionschikova has been a branch of the Moscow Centre for Palliative Care.

Support from the public health system

The hospice is funded by public funds and charitable organizations. In 2006, the Vera fund was established, which currently supports not only the first Moscow hospice but hospices and palliative departments throughout the country. The Foundation has become an effective associate of the hospice service and interacts energetically with the professional community, helping to improve the level of education of medical workers, with state authorities, initiating government and strategic decisions in the field of public health in the country, as well as with patients and their families.

Innovations

The first Moscow hospice was created in 1991 and served about 600 thousand inhabitants of the central district of Moscow. The wards of the hospice were oncological patients with advanced cancer who had not received specialized care before. In a hospice, unlike hospitals, patient's family and friends can stay with him or her round-a-clock and free. Hospice has become a centre for spreading the ideas of helping the dying and their families, mercy, compassion, selflessness, volunteering, charity, a life with dignity to the end.

Thanks to the First Director, Vera Millionschikova, the hospice has earned an impeccable reputation and has become the training base for the new hospices in Moscow, Russia, and the CIS countries. Vera Millionschikova passed away in 2010, but the hospice staff, largely consisting of her students, sacredly honours the traditions she has established and is actively moving forward.



REGION OF THE AMERICAS

Jamaica Hope Institute

Situational Context

The Hope Institute, located in the capital city of Kingston, is a small hospital providing care for cancer patients at any point on their journey. The hospital was built in 1963 by the Jamaica Cancer Society, and from its inception, has offered inpatient oncology care and hostel like care for patients living at a distance from the regional Radiotherapy Centre in the capital. In 1974 the hospital was taken over by the Ministry of Health and thus formally linked into the public sector. In 2002, with the appointment of a physician with training in both oncology and palliative medicine, a small specialist palliative care service was established.

Description of the model

The palliative care service is primarily hospital based with a focus on inpatient care. The care is provided by a small interdisciplinary team including doctors, nurses, a physiotherapist and a volunteer chaplain. In addition to inpatient care, a weekly outpatient clinic was established at the hospital in 2003, providing another level of patient support. The team from Hope also provides a once weekly oncology and palliative care clinic at the National Chest Hospital – for patients with lung and cardiovascular disease, and a weekly palliative care clinic at the Kingston Public Hospital, the island's only tertiary referral hospital. All care is provided free to the patient at the point of access, and patients are referred to the service from public and private sector facilities island wide.

Level of support from the existing health system

The Hope Institute is administered by the South East Region Health Authority under the auspices of the Ministry of Health. Both the Ministry and the Region are supportive of the role the hospital plays as the islands' sole provider of specialist palliative care, and, as a public sector facility, the annual budget is allocated by the Ministry of Health. The Hope Institute is also linked with the nearby teaching hospital and medical school at the University of the West Indies (UWI) principally through sharing of expertise and educational initiatives.

Innovations

Innovations at Hope have focused primarily on raising awareness of palliative care and on education and training. The first formal palliative care course for medical students from UWI was established at Hope in 2005. The hospital also offers short term placements or electives for physicians and nurses from other disciplines. In 2016, through linkages with local physicians, colleagues from Harvard Medical School, USA, and the UWI – the Jamaica Cancer Care and Research Institute (JACCRI) was launched. JACCRI is an NGO which has a principal focus on palliative care training and education both locally and in the Caribbean region. Members of JACCRI are working with the UWI School of Medicine to develop a formal training programme in palliative care and to have palliative medicine recognized as a medical specialty. Plans to develop a community based palliative care service alongside the Palliative Care Association of Jamaica are also underway. The Hope Institute has been chosen as one of six WHO Demonstration Project sites to be a model for the region.

Sustainability

As a public sector facility providing a specialist service, it is likely that the hospital will continue to receive government support for the foreseeable future. However, the sustainability and possible expansion of the current palliative care service will depend principally on the continued provision of adequately trained healthcare professionals with an interest in delivering either specialist or generalist palliative care. Support through public private partnerships, academic grants and philanthropy will be needed by NGOs such as JACCRI in order for their work to be sustained at a consistently high level.



Panama's Inclusion of Palliative Care into the Existing Primary Health Care System

Situational Context

Panama has increased the development in Palliative Care, through clear inclusion of Palliative Care within the State Health Policies. This has made it possible to implement a National Palliative Care Program based on Primary Care, the accessibility and availability of essential medicines in palliative care, education at undergraduate and postgraduate level and the active participation of Civil Society at a national and global level.

Description of the Model

The National Palliative Care Program of Panama is part of the model of care in the country, the strategy of Integrated and Integral Health Networks and the offer of Universal Health Coverage free of charge make this a model for how to integrate palliative care globally.

Level of Support from the Existing Health System

With close support from the Ministry of Health and the creation of a position at the MoH to lead palliative care development there is clear governmental will and support for palliative care in Panama. Rather than being outside the health system palliative care is being deliberately integrated into the existing structures and using support structures that are already in place.

Innovations

A fundamental strategy has been the harmonization of the two main public health providers, the Ministry of Health and the Social Security Fund, as well as work with the University of Panama which is key to the development of the Program in recent years with important achievements such as:

- Implementation as a model of care based on primary care
- Amendments to the Controlled Substances Act to include essential palliative medicines in the list of medicines in Panama;
- accreditation and approval of the Specialization Program in Palliative Medicine;
- annual evaluation system of the National Palliative Care Program from local to national levels, identifies opportunities for improving the quality of patient and family care.

As another aspect is collaboration with global and national non-governmental organizations such as the Latin American Association of Palliative Care, the IAHP, the WHPCA, and the Panamanian Association of Palliative Care and teamwork by each and every one of the members. Every day the specialists and generalists in the various branches of health have incorporated and continue to incorporate palliative care into their models and protocols of care.

Sustainability

While resources are always limited being integrated into the existing health care system ensures sustainability, while encouraging the commitment of health professionals, volunteers, strategic allies, who have worked with commitment, dedication, excellence and love since the beginning of Care Palliative in the year 1989 to date.



**WESTERN
PACIFIC
REGION****Australia: Healthy End of Life Project (HELP): Creating Collaborative Cultures at the End of Life****Situational Context**

La Trobe University Palliative Care Unit founded public health approaches to palliative care in 1999, recognizing that wellbeing, including at the end of life, is shaped by where we live, work, learn and socialize. We provide leadership in practice, research and education and partner at national, state and local government levels in Australia providing direction for policy and systems reform and building capacity across jurisdictions and sectors and within communities.

Description of the model

The Healthy End of Life Project (HELP) is a product of research and practice. It addresses key findings that citizens are reluctant to ask for or accept help from family and social networks while providing end of life care, and that offers to help are often inept. These norms combine to undermine a community's capacity to contribute to improved end of life experiences and outcomes in diverse social settings.

Level of support from the existing health system

HELP is being used by over 30 stakeholders across a range of local and international contexts. Health and palliative care agencies are using HELP to support the development of evidence-based health promotion initiatives within partnerships and communities. HELP resources such as 'social network enhancement activities' and 'community asset mapping' complement the delivery of palliative care services and promote patient choice by connecting informal care networks with formal services.

Innovations

HELP is both an implementation and evaluation framework. It is designed to promote recall, uptake and capture interest, and to make accessible to a variety of stakeholders the evidence-base that will promote successful outcomes. Healthy End of Life Participation, Partnerships, Planning, Programs, Practice, Policy, Place and People (the eight Ps) name structures that should be considered when creating collaborative settings through challenging social norms and using an asset-based approach.

Sustainability

HELP is an asset-based model that identifies and networks the existing strengths of a community or sector so that a framework can be wrapped around their valuable contributions to improving end of life care outcomes. Healthy End of Life Partnerships, Policy and Participation embed principles for sustainable outcomes. Inserting end of life matters into the existing structures of sectors, settings, community networks, policies and jurisdictions increases the sustainability of outcomes.



Culcairn Local Health Advisory Committee and Community Members are supported by the Murrumbidgee Primary Health Network to implement La Trobe University's HELP Framework (New South Wales, Australia)



The Community Houses Association of the Outer East Suburbs (CHAOS) discuss the implementation of La Trobe University's HELP Framework in the Neighbourhood House Sector of Australia (Victoria, Australia)

Hospis Malaysia

Situational Context

Hospis Malaysia is a charitable community palliative care service in Kuala Lumpur founded in 1991. Starting from a volunteer driven model, it has grown to become the largest community palliative care service in Malaysia caring for about 2000 patients annually with 36 staff and operating expenses of about USD 1 million annually. Funding is almost entirely through public donations as its palliative care services are provided free of charge.

Description of the model

We are a clinical service providing palliative care in the community underpinned by education, research and advocacy. The clinical service provides care for about 400 patients at any one time and includes access to medicines, equipment and 24-hour coverage. Referrals are accepted based on palliative care needs. Providing post-graduate and undergraduate education with 5 universities ensures clinical practice remains up to date. Palliative medicine specialist trainees spend 6 months learning community palliative care. A strategic public engagement and advocacy programme complements and raises the profile of palliative care nationally.

Level of support from the existing health system

The Malaysian health structure is not really conducive to a community palliative care structure. However, over the years through efforts at communication and advocacy, a good network of supportive advocacy has developed amongst palliative care, cancer, pain, and several health-based organisations that sees mutual strength in working together. Collaboration with universities has enhanced the status of palliative care and led to increased research activity. A visit by the Duke and Duchess of Cambridge in 2012 brought national and international attention to Hospis Malaysia and has led to increasing national engagement with the Ministry of Health in developing a national strategy.

Innovations

Hospis Malaysia has always embraced innovation in care and practice. Introducing needs-based care, cultivating professional palliative care and providing 24-hour cover for services was innovative in the 90s in Malaysia. We have also established a multi-skilled interdisciplinary team where our palliative care nurses are taught the skill sets to function as basic clinicians, social workers, and paediatrics to provide care. Establishing a strong management structure provided an effective base for growth and innovation. Our public advocacy program led to the production of a palliative care needs assessment in Malaysia. A common symbol for palliative care was developed and has been adopted by others. In 2014, we developed our own web base electronic medical record system, enabling instantaneous capture of and access to patient records which has also become useful for audit and research.

Sustainability

Having a service that is dependent virtually 100% on public donations is challenging. With no statutory government funding and insurance payments, income generation requires a significant amount of thought and effort. Understanding patients and caregivers' experiences and their advocacy has been key in driving relevant messages for funding. In an environment where palliative care has to compete against other charities, positive messaging backed by evidence of good care outcomes is important. Public engagement requires strategic thinking and key investment and thus far has enabled Hospis Malaysia to grow significantly over the past 25 years.



The story of the Duchess of Cambridge with a paediatric patient at Hospis Malaysia generated worldwide attention in 2012



In a country where home visits are uncommon, community palliative care visits with good care outcomes asks the question, 'why this isn't the norm?'

Palliative care in Mongolia

Situational Context

Mongolia is a large country with a population of 3.2M. Life expectancy at birth is 72 years for women and 64 years for men. The leading causes of mortality were circulatory diseases (34.3%), cancer (24.3%), & injuries and poisonings (16.8%). In 2016, 78.8% of cancer patients were diagnosed with late stage disease (III or IV), and 85.4% of cancer cases survived for less than a year after the diagnosis. Since 2000, Mongolia has established the foundation measures for a national palliative care program with the creation of the Mongolian Palliative Care Society and the Palliative Care Department and has made several significant achievements:

Description of the Model

1. *National Laws & Policies:* Palliative care is included in Mongolia's Health Law, Health Insurance Law, Social Welfare Law, National Cancer Control Program, National NCD Program and National Medical Services Law. In addition, palliative care standards were approved in 2005, pain management guidelines in 2012, and paediatric palliative care ethical guidelines in 2017.
2. *Palliative care education programs* included in:
 - The undergraduate curriculum in all medical universities for general practitioners, nurses, & social workers
 - The postgraduate curriculum in all medical universities for doctors, nurses.
 - Specialization on palliative care for doctors by 6 months program, for nurses by 3 months program
3. *All Essential palliative medicines* are available in Mongolia since 2006
4. *Palliative care services:*
 - Six outstanding hospice units in Ulaanbaatar have 60 beds;
 - During 2010-2015, with the support of "Cancer Free Mongolia Foundation,"
 - all 21 province hospitals and all the nine districts hospitals in Ulaanbaatar established up to five palliative care beds.
 - The MoH approved 596 additional palliative and nursing care beds (3% of total hospital beds) for cancer and non-cancer and in 2018-2019 approved 794 palliative care beds throughout the country. All these beds are covered by Health Insurance and free to patients.

Level of support & integration into the existing health care system

Our palliative care services are integrated into the health system very closely and are supported by health insurance. Palliative care inpatients beds in the 21 provinces of Mongolia and 9 districts of Ulaanbaatar which were approved by the Minister of Health are receiving health insurance throughout the country. Cancer patients received opioids for pain management free (supported by health insurance).

The Mongolian Palliative Care Society coordinates palliative care advocacy, education, and public awareness. The six hospices in the Capital are supported by Korean and Christian organizations and Rotary International. The Paediatric Oncology Haematology Centre with 5 palliative care beds was established by activities of Ajaa Geegen and donations from international organizations.

Innovations to Highlight

- A paediatric palliative care unit with 5 beds was opened in 2014 in the Paediatric Oncology Haematology Centre and in 2017 approved ethical guide for paediatric palliative care.
- A palliative care ward for patients with HIV and multiple drug resistant tuberculosis opened in 2017 and the doctors, nurses, & team were educated on palliative care. Soon a textbook on palliative care for HIV patients will be published.
- Since 2005 we have 4 palliative care beds in the prison hospital, which was approved by the Ministry of Health.

Sustainability

The Palliative care system in Mongolia, which is integrated with the health system, health insurance system, social welfare system, and education system ensures sustainable palliative care.



**EASTERN
MEDITER-
RANEAN
REGION****Oman Palliative Care Association,
Sultanate of Oman****Situational Context**

In Oman, palliative care is still in its infancy and consequently many acute hospital beds are blocked by patients who would benefit from this specialised form of care with no available alternative. Unblocking expensive beds in the Sultanate would enable them to work more efficiently and be more cost effective whilst at the same time improving the quality of life for palliative care patients. There is also scant provision for nursing in the community and death at home is often regarded as a suspicious circumstance. There are also cultural and religious challenges to be reconciled in this rapidly evolving Muslim state.

Description of model

The Oman Palliative Care Association (OPCA) was established in 2018. The major aim of the association at this early stage is to raise awareness and campaign for change. OPCA was launched via a public seminar for a cross-section of stakeholders. <https://www.youtube.com/watch?v=fZawG0b6o2k>

The key-note speaker was Professor Richard Harding together with his team from the Centre for Global Health Palliative Care, Cicely Saunders Institute College King's College London. Kings is also working in Jordan & Malaysia.

The event received good press and TV coverage.

Level of support from the existing health system

Working in partnership with King's College London has helped to put palliative care firmly on the agenda. The initiative has the full support of the Ministry of Health and the meeting was opened by the Minister of Health, HE Dr. Ahmed Al Saidi. Most members of the board are young medical professionals and community leaders. Private sector healthcare in Oman recognises the potential for palliative care and a small number of "rehabilitation centres" have recently been established and agencies offering home nursing care.

Innovations

As a result of this initiative Oman is now one of six countries selected to participate in the WHO Palliative Care Global Evaluation Project.

This will further underline the value of palliative care and help with implementation and change.

The role of OPCA is to offer support in any way we can and to continue to link up and learn from other models worldwide whilst continuing to raise awareness in Oman.

Sustainability

King's College team have emphasised the importance of training and capacity building. The aim is to establish palliative care as a specialty within the Ministry. The emphasis will always be on providing quality care and measuring outcomes. There will also need to be some changes in legislation relating to the availability of opioids & place of death to allow patients to be treated more easily within the community.



Stories from People Living with Palliative Care Needs (Names used with permission)

Ethiopia

Etsegenet Asefa had severe physical pain and symptoms, but also emotional, spiritual and psychosocial pain due to her cancer diagnosis. Palliative care relieved her suffering, brought comfort to her and her family, and gave her confidence and hope once more.

My name is Etsegenet Asefa, I'm 50 years old and I access palliative care at Hospice Ethiopia.

After my diagnosis, I found myself in a severe physical, psychosocial & spiritual distress. But after accessing palliative care, my suffering was holistically relieved. I have comfort and improved health status. I am now able to help others by giving care and raising awareness for those who were once in my shoes. My family are very happy, satisfied and at peace with my improvements and that am alive now with no pain.

Palliative care must be accessible because there are numerous people suffering from life threatening illness in developing counties like Ethiopia, especially women with breast and cervical cancer. After I accessed palliative care, I got the initiative, courage and psychological readiness to start from the beginning again. I used to give up on myself, I never saw that I would be here today. I advise and encourage people to not give up on themselves.



India

Ashla Rani is a young woman from India, who accesses palliative care, and also works in the field. She met with an accident in 2010 when she was 28 years old. She was admitted to different hospitals for the next four years, being treated by specialists in neurology, rehabilitation and other medical disciplines.

She says: “During these years. I was always given the best treatment possible. I have no doubts about it. My spinal cord injury received everyone’s attention. What was missed was (in)significant issues like my constipation, post-traumatic stress disorder, loss of hope. I still remember faking a headache to meet a senior doctor to talk about my constipation. I was so embarrassed when he came to the waiting area and asked me about my headache in front of many others. Ashla as a person was ignored except for some rare occasions when a junior doctor or physiotherapist asked about my job and encouraged me to get back to it.” Ashla moved to Pallium India in 2014 as a care recipient and volunteer. She was touched by the way in which her mother (her primary caregiver) received equal attention and care.

Ashla says: “My mother was asked her name, how she was, whether she had any medical issues, how did she cope with everything she had to go through as a mother and sole caregiver of someone who is dependent for all activities of daily living. She was just a bystander during those four years when I was getting treatment and rehabilitation after my spinal cord injury (except when she was very ill with vertigo or fever a couple of times) in other hospitals. And all of a sudden, she was treated as a person, instead of a nameless bystander.

“Palliative care ensured that both my mother and I are given importance. She was offered help to provide care for me.”

Ashla started working with Pallium India after accessing care at the organisation. She says: “It gave me a purpose to live. In my view, living really means not only being given comfort, but also being able to contribute to the family and to the society. In palliative care, I am given that opportunity. Here and now, I enjoy life.”



South Africa

Huyaam Samuels is a young South African woman living with a rare life-limiting condition called Pseudo-Achondroplasia and Hypermobility Syndrome. She accesses palliative care for the management of pain and physical symptoms, as well as psychological support. She says: “With palliative care, I am supported to live a good quality of life in the context of my health difficulties.” With the support of her palliative care team, Huyaam is able to attend university, and take part in physical activities such as yoga.

Huyaam is an outspoken advocate for palliative care, volunteering with a children’s palliative care organisation as a Youth Ambassador and working with the Worldwide Hospice Palliative Care Alliance to advance palliative care across the globe. She says: “Being listened to and consulted on palliative care issues, and having the opportunity to make my voice heard, makes me feel empowered and that I really matter.”

“People like me, with direct experience of serious illness are a vital part of the solution. We must be engaged and involved in making positive change to improve access to quality palliative care services worldwide.”



What are the available resources at global/regional levels to support palliative care policies, programmes and research in low–middle income countries?

Stephen Connor, Julia Downing, Liliana de Lima

Resources for palliative care development are limited worldwide. In spite of this, considerable private efforts, goodwill and community support have sustained and helped build palliative care worldwide. In this chapter the educational, financial, and human resources devoted to meeting the need for palliative care will be discussed along with some evidence for cost–effectiveness.

Financial resources devoted to palliative care

Exact figures on the funds dedicated to the provision of hospice and palliative care services are not known. There are some examples of resource allocation, mainly in Western countries, that provide a partial picture of the need for resources.

Several studies have estimated the cost of care in the last year of life to between 25–30% of all medical expenditures.^{108 109 110} The US Medicare programme for those over 65 years spent a total of \$705.9 billion US dollars in 2017, including \$17.9 billion for hospice care. Palliative care outside of hospices in the USA is mostly hospital-based consultancy services. There are reportedly 2160 hospitals in the US that have palliative care services, though the amount of money spent in these programmes is not known. In Canada hospice palliative care is 50% funded by charitable donations.

On average, adult charitable hospices in England receive approximately one-third of their costs from the government or National Health Service (NHS), although the actual amount of state funding for local charitable hospices around the United Kingdom varies considerably. Children's hospices receive far less funding support from government or the NHS.

Is palliative care cost effective? Studies have demonstrated the cost–effectiveness of hospice and palliative care services. Overall, the utilization of both hospital-based and in-home hospice and palliative care services significantly reduced the cost of care, while providing equal if not better-quality care. However, studies to date are primarily from developed countries. (See literature review in Appendix 4).

Philanthropic support

Many charitable organizations have a history of supporting hospice and palliative care development locally. There are very few that remain active in supporting global palliative care. The most prominent one, Open Society Foundations, is currently phasing out its International Palliative Care Initiative. New philanthropic support for global palliative care is urgently needed.

Open Society Foundations, International Palliative Care Initiative – Palliative care is a holistic health-care approach that improves the quality of life for patients and their families by addressing the psychosocial, legal, and spiritual problems associated with life-threatening illness. Open Society Foundations supports efforts to make palliative care a sustainable, essential part of public health systems worldwide. <http://www.soros.org/topics/palliative-care>

Multilateral and Bilateral Support

Government support for international health includes some support for palliative care and related health-care services. The largest of these agencies includes the Global Fund, the President's Emergency Plan for AIDS Relief (PEPFAR), the United Kingdom's Department for International Development (DFID), and individual country commitments to palliative care development. Exact funds committed towards palliative care are not available.

Research support

Every specialized component of health care needs a growing body of research to advance its field. Though hospice and palliative care is gaining recognition in many countries and there is a growing body of knowledge and literature, there has been very limited funding for research. The following are a few examples of palliative care research initiatives:

- In the USA less than 1% of government research funding is directed towards topics relevant to palliative care. The National Palliative Care Research Centre (www.npcrc.org) advocates in the US for palliative care research.
- The European Association for Palliative Care has a strong focus on palliative care research through its research network. <http://www.eapcnet.eu/Themes/Research.aspx>
- The Cicely Saunders Institute of Palliative Care, Policy, and Rehabilitation at Kings College London has a well-developed research and teaching program <https://www.kcl.ac.uk/cicelysaunders/about/index>
- The Lien Centre for Palliative Care has research programmes looking into clinical, social and cultural aspects of palliative care in Singapore and Asia. It also focuses on palliative care education and the development of health-care professionals <http://www.duke-nus.edu.sg/research/Centres/lien-centre-palliative-care>

WHO Resources for Planning and Implementing Palliative Care

The World Health Organization has produced a number of important resources for palliative care. These include:

Planning and Implementing Palliative Care

1. Planning and implementing palliative care services: a guide for programme managers (2016). Available at: <https://www.who.int/publications/i/item/planning-and-implementing-palliative-care-services-a-guide-for-programme-managers>
2. Palliative Care for noncommunicable diseases: a global snapshot (2019). Available at: <https://www.who.int/publications/i/item/palliative-care-for-noncommunicable-diseases-a-global-snapshot>
3. Integrating palliative care and symptom relief into primary health care: A WHO guide for planners, implementers, and managers (2018). Available at: <https://www.who.int/publications/i/item/integrating-palliative-care-and-symptom-relief-into-primary-health-care>
4. Integrating palliative care and symptom relief into paediatrics (2018). Available at: <https://www.who.int/publications/i/item/integrating-palliative-care-and-symptom-relief-into-paediatrics>
5. Integrating palliative care and symptom relief into the response to humanitarian emergencies and crises (2018). Available at: <https://www.who.int/publications/i/item/integrating-palliative-care-and-symptom-relief-into-the-response-to-humanitarian-emergencies-and-crisis>

Pain Management

Cancer pain management

- WHO Guidelines for the pharmacological and radiotherapeutic management of cancer pain in adults and adolescents (2019). Available at: <https://www.who.int/ncds/management/palliative-care/cancer-pain-guidelines/en/>

HIV/AIDS

- HIV/AIDS Treatment and Care: WHO Protocols for CIS Countries (2004) Palliative Care Chapter pp. 63-79. Available at: https://www.euro.who.int/__data/assets/pdf_file/0011/153659/E83863.pdf
- Pocket Book of Hospital Care for Children: Guidelines for the management of common childhood illnesses 2nd Edition (2013). Chapter on palliative and end-of-life care for children with HIV, pp 250. Available at: https://www.who.int/maternal_child_adolescent/documents/child_hospital_care/en/
- Palliative Care: symptom management and end-of-life care. In Integrated Management of Adolescent and Adult Illness (2004). Available at: <https://www.who.int/3by5/publications/documents/en/genericpalliativecare082004.pdf?ua=1>
- A Community Health Approach to Palliative Care for HIV/AIDS and Cancer Patients in Sub-Saharan Africa (2004). Available at: <https://apps.who.int/iris/bitstream/handle/10665/42919/9241591498.pdf?sequence=1>

Tuberculosis

- Ethics Guidance for the Implementation of the End TB Strategy (2017). Chapter on Palliative and end-of-life care. pp. 25. Available at: <https://www.who.int/tb/publications/2017/ethics-guidance/en/>
- Guidelines for the programmatic management of drug-resistant tuberculosis (2008). These guidelines contain brief mention of key palliative care needs and refers readers to the IMAI palliative care guidelines. Available at: https://apps.who.int/iris/bitstream/handle/10665/43965/9789241547581_eng.pdf?sequence=1
- Companion Handbook to the WHO Guidelines for the programmatic management of drug-resistant tuberculosis (2014) Chapter 13 on palliative and end-of-life care. pp. 193-7. Available at: https://www.who.int/tb/publications/pmdt_companionhandbook/en/

Opioid Access

- Access to Controlled Medicines Programme - Framework https://www.who.int/medicines/areas/quality_safety/Framework_ACMP_withcover.pdf?ua=1
- Medicines for Palliative Care in WHO Essential Medicines List <https://apps.who.int/iris/bitstream/handle/10665/330668/9789241210300-eng.pdf?ua=1>
- Web statement on pain management publications under revision. (2019). Available at: https://www.who.int/medicines/areas/quality_safety/guide_perspainchild/en/

General Medical Devices for Palliative Care and End-of-Life Care

- WHO List of priority medical devices for cancer management (2017). Chapter on Palliative Care & end-of-life care. PP 140-49. Available at: <https://apps.who.int/iris/bitstream/handle/10665/255262/9789241565462-eng.pdf?sequence=1> (Section 7.2.1)

Older People

- Palliative Care for Older People: Better Practices (2011). From WHO EURO. Available at: https://www.euro.who.int/__data/assets/pdf_file/0017/143153/e95052.pdf
- What are the palliative care needs of older people and how might they be met? (2004) WHO EURO. Available at: https://www.euro.who.int/__data/assets/pdf_file/0006/74688/E83747.pdf
- Palliative Care: The solid facts (2004) WHO EURO. Available at: https://www.euro.who.int/__data/assets/pdf_file/0003/98418/E82931.pdf

Other Noncommunicable Disease

- Global Action Plan for the Prevention and Control of Noncommunicable Diseases 2013-2020. Available at: <https://www.who.int/nmh/publications/ncd-action-plan/en/>

The Worldwide Hospice Palliative Care Alliance
<http://www.thewhpc.org/> has available the following reference documents:

The Palliative Care Toolkit: Improving care in resource-limited settings was written to empower health workers in resource-poor settings to integrate palliative care into the work they are doing. Available in the following languages:

Main Page: <http://www.thewhpc.org/resources/category/palliative-care-toolkits-and-training-manual>

Palliative Care Toolkit 2016

This toolkit has been written to empower health workers in resource-poor settings to integrate palliative care into the work they are doing by grafting the missing elements of care onto what is already in place. The WHPCA, Hospice UK and Palliative Care Works have led this updating of the Palliative Care Toolkit published in 2008 to reflect new knowledge and practice.

[Training Manual - English 2016](#)

An earlier version of the Toolkit and Training manual was translated to the following languages:

[Palliative Care Toolkit - Swahili](#)

[Palliative Care Toolkit - Bengali](#)

[Palliative Care Toolkit - French](#)

[Palliative Care Toolkit - Portuguese](#)

[Palliative Care Toolkit - Spanish](#)

[Palliative Care Toolkit - Vietnamese](#)

[আসুন, প্যালিয়েটিভ কেয়ারকে জানি - Let's Get to Know Palliative Care \(Bangla\)](#)

[Palliative Care Toolkit - Russian](#)

[Training Manual - Bengali](#)

[Training Manual - English](#)

[Training Manual - French](#)

[Training Manual - Portuguese](#)

[Training Manual - Spanish](#)

Additional WHPCA Resources

These resources are to help, support and inspire you to take action

These resources are focussed on supporting the development of hospice and palliative care. They are likely to be of most interest to those working, or interested in working, in palliative care, health and development.

If you are a member of the public and you are looking for patient and carer support and resources, contact your national association or local hospice or palliative care service.

For global news, views and inspiration relating to hospice and palliative care, visit www.ehospice.com

Free Book: [Building Integrated Palliative Care Programs and Services](#) (1)

[Covid-19 Resources](#) (40)

[World Hospice and Palliative Care Day 2019](#) (42)

[Global Atlas of Palliative Care at the End of Life](#) (3)

[Laws, regulations and national strategies](#) (33)

[Disease specific plans and guidance](#) (20)

[Country reports and needs assessments](#) (19)

[Standards, clinical guidelines and protocols](#) (50)

[UN guidelines, documents and strategies on palliative care](#) (5)

[National association strategic plans](#) (2)

[Advocacy resources](#) (40)

[Media resources](#) (11)

[Fundraising resources](#) (4)

[WHPCA publications and reports](#) (24)

[WHPCA position statements](#) (7)

World Hospice and Palliative Care Day Resources

<http://www.thewhpca.org/world-hospice-and-palliative-care-day>

The International Association for Hospice and Palliative Care has the following resources:

IAHPC Projects

<https://hospicecare.com/what-we-do/projects/>

IAHPC Resources

<https://hospicecare.com/what-we-do/directories/>

IAHPC Publications

<https://hospicecare.com/what-we-do/publications/>

Policy Frameworks and Norms

<https://hospicecare.com/policy-and-ethics/human-rights/>

Ethical Issues

<https://hospicecare.com/policy-and-ethics/ethical-issues/>

International Children’s Palliative Care Network <http://www.icpcn.org/> has the following resources:

- ICPCN E-Learning Program <http://www.icpcn.org/icpcns-elearning-programme/>
 - Introduction to children’s palliative care
 - Pain assessment and management for children
 - Childhood development and play in children’s palliative care
 - Communicating with children and emotional issues in children’s palliative care
 - End of life care in children’s palliative care
 - Grief and bereavement in children’s palliative care
- ICPCN Publications and Resources <http://www.icpcn.org/icpcn-publications-resources/>
 - [The ICPCN Charter](#)
 - Palliative Care and Universal Health Coverage Facts Sheet June 2018
 - [Touching Rainbows](#)
 - [Myths and Facts in Children’s Palliative Care](#)
 - [ICPCN Research Papers & Journal Articles](#)
 - [ICPCN / UNICEF Research](#)
- A Really Practical Handbook of Children’s Palliative Care – For Doctors and Nurses Anywhere in the World <http://www.icpcn.org/a-really-practical-handbook-of-childrens-palliative-care/>
- Other Resources <http://www.icpcn.org/other-resources/>

The following educational institutions offer graduate educational programmes in palliative care:

Edge Hill University – Ormskirk, UK

- MSC Integrated Palliative and End of Life Care
https://www.edgehill.ac.uk/courses/integrated-palliative-and-end-of-life-care-msc/?utm_source=find%20a%20masters&utm_medium=course%20listings&utm_campaign=always%20on%20pg&utm_content=MSc%20palliative%20and%20end%20of%20life%20care

Flinders University – Adelaide, South Australia

http://www.flinders.edu.au/courses/postgrad/ppc/ppc_home.cfm

- 6 month certificate
- 1 year diploma
- 1.5 year masters

Kings College – Cicely Saunders Institute – London, United Kingdom

<http://www.csi.kcl.ac.uk/study-with-us.html>

- Doctorate in Palliative Care Research
- MSc in Palliative Care
- PG Diploma and PG Certificate

Lancaster University – United Kingdom

<https://www.lancaster.ac.uk/study/postgraduate/postgraduate-courses/palliative-care-phd/>

- Doctorate in Palliative Care

Makerere University and the Institute of Hospice and Palliative Care in Africa (IHPCA) at Hospice Africa Uganda, Kampala, Uganda

- Bachelor of Science in Palliative Care
<https://courses.mak.ac.ug/programmes/bachelor-science-palliative-care>
- Master of Science Degree in Palliative Care
<http://uganda.hospiceafrica.or.ug/index.php/education/study-programmes>

Newcastle University, Medical Sciences Graduate School

- Palliative Care – MSc/PG Dip/ PG Cert
https://www.ncl.ac.uk/postgraduate/courses/degrees/palliative-care-msc-pgdip-pgcert/?utm_source=referral-findamasters&utm_medium=course-listing&utm_content=palliative-care-msc-pgdip-pgcert&utm_campaign=PG3PL-findamasters#profile

Norwegian University of Science and Technology – Trondheim, Norway

- Doctorate in Palliative Care
<https://www.ntnu.edu/studies/phpalc>

Queen Margaret University, School of Health Sciences - Edinburgh, Scotland

- MSc Person-Centred Practice (Palliative Care)
<https://www.qmu.ac.uk/study-here/postgraduate-study/2020-postgraduate-courses/msc-pgdip-person-centred-practice-palliative-care/>

Trinity College Dublin, Ireland

- Masters in Palliative Care

<https://www.tcd.ie/courses/postgraduate/az/course.php?id=DPTNM-PCAR-1P09>

University of Cape Town, South Africa

School of Public Health and Family Medicine

- Diploma in Palliative Medicine http://www.publichealth.uct.ac.za/phfm_postgraduate-diploma-palliative-medicine
- Masters of Philosophy in Palliative Medicine http://www.publichealth.uct.ac.za/phfm_master-philosophy-palliative-medicine

University of Cardiff – Wales, United Kingdom

- Masters in Palliative Medicine for Health Care Professionals

<https://www.cardiff.ac.uk/study/postgraduate/taught/courses/course/palliative-medicine-for-health-care-professionals-msc-part-time>

University of Dundee School of Medicine, Dundee, Scotland

- Public Health (Palliative Care Research) MPH

<https://www.dundee.ac.uk/postgraduate/public-health-palliative-care-research>

University of South Wales Faculty of Life Sciences and Education

- PGCert Palliative Care (Distance Learning)

<https://www.southwales.ac.uk/courses/postgraduate-certificate-palliative-care-distance-learning/>

An international listing of education and certificate programmes in palliative care is maintained by the International Association for Hospice and Palliative Care at:

<http://www.hospicecare.com/global-palliative-care/global-directory-of-education-programs/>

(See Appendix 2 for additional organizational and other resources)

What is the way forward?

Claire Morris & Helena Davies

Palliative care is a fundamental component of national health systems and an essential service within Universal Health Coverage reforms. It is highly effective at relieving the pain and suffering of people living with and affected by life-limiting illness, optimizing their quality of life from early in the course of their disease until the end of their lives. COVID-19 laid bare the devastating impact on people's lives of failure to integrate palliative care into health systems. With an ageing global population and rising incidence of communicable and non-communicable diseases, the need for palliative care is increasing. Yet, millions of people worldwide cannot access the compassionate, palliative care that they need.

In each global region, countries have shown how palliative care can be made available to those who need it, including through its integration into Universal Health Coverage reforms. As national leaders strive to improve health care systems to ensure essential health services for all those who need it, it is crucial that people with palliative care needs are not neglected.

Important recommendations for national governments to ensure access to palliative care for all those that need it are:

1. Financing

The financing of palliative care should be integrated into national health system budgets at all levels of care. As countries progress with their Universal Health Coverage reforms, it is vital that an essential package of palliative care is included. Mechanisms should be put in place to allow financial information on budgeting and expenditure on palliative care within health systems to be made available for scrutiny. Evidence to date suggests that palliative care is a cost-effective intervention when compared with standard care for individuals at the end of life.

2. Essential medicines

Palliative care medications as outlined in the WHO essential palliative care medications list should be available to all those who need them. This is particularly important for opioids which are crucial for pain treatment and managing severe respiratory distress. Access to inexpensive immediate and sustained release morphine is necessary for palliative care patients. To achieve this, countries can work with International Narcotics Control Board (INCB), United Nations Office on Drugs and Crime (UNODC), WHO and civil society partners to address regulatory barriers and improve medication supply and management systems.

3. Health systems governance

Palliative care should be included in the policies and structures of national health systems at all levels with accompanying accountability mechanisms. This is essential to ensure appropriate quality of care and that the most vulnerable and marginalized in societies are reached.

4. Health and social care workforce

Palliative care should be integrated in the curricula of all new health care professionals and community health care workers training. In addition, all existing health care professionals and workers should be trained in essential palliative care as a matter of urgency. Addressing the training gap in those delivering social care to individuals having palliative care is also a matter of high importance.

5. Statistics and information systems

The monitoring of access to palliative care should be undertaken at all levels of care to ensure that all those who need it receive it. This means ensuring appropriate universally agreed indicators and data collection mechanisms as well as accessible reporting at the local, national and global level. Regular scrutiny and publication of the data output is essential.

6. Service delivery and safety

Essential palliative care should be available where the person is, whether that is in the home, hospitals, or community settings such as care homes and hospices. Ensuring that people with palliative care needs are safe and cared for with dignity and respect is a crucial responsibility of national health systems. This must include those who are systematically left behind including children, older people, prisoners, sex workers, drug users, refugees, people experiencing homelessness, and LGBT+ communities.

7. Community action

Communities play an important role in access to palliative care globally. This is done through providing care, e.g. volunteer community caregivers and family members, through to community members who engage and support others to understand the importance of palliative care and what it does. The crucial role of compassionate communities, including people living with palliative care needs, should be recognized and supported. It is especially important to understand and address the particular gendered nature of caregiving which falls on women and girls in communities and families without recompense, support and equipment, contributing to continued gender inequalities

8. Lived experience

It is also crucial that there is an explicit commitment to the inclusion of the voice of those with lived experience in developing, delivering and monitoring palliative care at all levels. This includes development of training and teaching materials as well as, for example, indicators of quality of care and understanding of barriers to delivery of adequate palliative care.

9. Research

Continuing to establish a robust evidence base is a crucial component to building commitment to greater access to palliative care for those who need it. The research agenda should be funded to continue to examine the access, outcomes and cost-effectiveness of palliative care and its impact on people's lives and health systems.

Further recommendations

Technical agencies

- All technical agencies who are leading on global health initiatives, including UHC technical assistance and reform support, should review their existing guidance, programmes, funding and monitoring to ensure palliative care is included as an essential part of the spectrum of healthcare services.
- Cross-technical agency initiatives such as the Access to covid-19 tools (ACT-Accelerator) should ensure that health systems are strengthened and cover the life-course from prevention, promotion, treatment, rehabilitation and palliative care.
- INCB should continue and reinforce its efforts to ensure that countries guarantee adequate availability of controlled substances for medical use, as required by the UN drug conventions.
- UNICEF should take a leadership role in promoting and extending the inclusion of palliative care for children by developing palliative care guidance, monitoring access to children's palliative care, and promoting palliative care educational development.

Bilateral donors, funders and foundations

- Provide global leadership on palliative care ensuring allocation of funds to palliative care as a fundamental component of the health-care system, UHC reforms and a basic human right for people living with life-limiting conditions and their carers.
- Ensure monitoring and evaluation of funded programmes include assessment of both access to palliative care and the quality of life of people living with life-limiting conditions.
- The Global Fund on HIV, TB and Malaria should strengthen its health systems strengthening strategic objective to ensure that health systems are providing the essential spectrum of essential health services including palliative care. This should benefit all people with chronic and life-threatening conditions including those with HIV and MDR/XDR TB.

Civil society and communities

- Build demand for and understanding of palliative care in homes, communities and countries and support accountability from government, donor agencies and technical agencies to ensure access to care.
- Ensure that the voices of the most marginalized and vulnerable are heard and they are not left behind.

Conclusion

As Universal Health Coverage reforms take place, it is critically important that essential palliative care services are included as an integral part of the healthcare spectrum. Collective action and collaborations between governments, technical agencies, philanthropists, academia, civil society and communities is necessary to ensure that everyone accesses the palliative care they need when they need it. It is time to invest in our health systems globally and radically rethink them to meet the needs of those with chronic conditions. Those with palliative care needs, who are some of the most hidden and vulnerable in our societies, cannot continue to be left behind.

APPENDIX 1

Methodology for Global Atlas of Palliative Care, 2nd Edition

The data used in this Atlas comes from existing published data. Some estimates are derived from existing databases and studies.

Chapter 1: From published articles, and data on diagnoses requiring palliative care came from a Delphi Study conducted by WHO. Subsequently modified based on methodology and results of the Lancet Commission Report on Palliative Care and Pain Relief¹⁹ <http://www.thelancet.com/commissions/palliative-care>

Chapter 2: All estimates of the actual need for palliative care based on methodology and results of the Lancet Commission Report on Palliative Care and Pain Relief.¹⁹ Institute for Health Metrics & Evaluation Global Burden of Disease 2017 data was used for the calculations. Mortality, and Prevalence of diseases/ conditions, as well as Population data used in Palliative Care Need and SHS estimations were extracted from: Global Burden of Disease Study 2017 (GBD 2017 from IHME) data resources: <http://ghdx.healthdata.org/gbd-2017>. World Bank Income Groups: WB 2017-2018 Income Group Classification: FY18. Disease Classification used in Palliative Care Need and SHS estimations: WHO ICD-10 Classification. Population data used to compute Patients and Services rates: IHME 2017 Population Estimates: <http://ghdx.healthdata.org/gbd-2017>

Chapter 3: Published literature on barriers and for opioid usage data used INCB data summarized by the WHO Access to Controlled Medicines Programme. This data is compiled by the Walther Centre for Global Palliative Care at Indiana University in cooperation with the International Narcotics Control Board. The data is published online at: <http://painpolicy.iu.edu>

Chapter 4: We used published results of WHO's Report "Palliative Care for Noncommunicable Diseases: A global snapshot 2020." We also used the results from a paper titled: Mapping Levels of Palliative Care Development in 198 Countries: The situation in 2017 to report the six levels of palliative care development globally.⁸⁵ Calculation of the numbers of palliative care service providers and patients served comes from a paper titled "Estimating the number of patients receiving specialized palliative care globally in 2017"¹⁰⁵

Children's palliative care development estimates came from data published in the following article: "Global development of children's palliative care: the picture in 2017."⁸⁶

Chapter 5: We used invited selected palliative care services to submit descriptions for different models of palliative care programming. These reports highlighted innovations in the financing and sustainability of these models. We also included individual stories submitted by selected people living with palliative care needs.

Chapter 6: Provides an inventory of existing resources including documents, websites, journal resources, educational programmes, and an audit of programme funding from the charitable sector in low–middle income countries.

Chapter 7: Summarizes the previous sections and provides narrative conclusions and recommendations.

APPENDIX 2 **Organizational resources**

African Palliative Care Association

<https://www.africanpalliativecare.org/>

APCA's mission is to promote and support affordable and culturally appropriate palliative care throughout Africa.

American Academy of Hospice and Palliative Medicine

www.aahpm.org

The Academy is the professional organization for physicians specializing in hospice and palliative medicine.

Asia Pacific Hospice Palliative Care Network

Singapore

www.aphn.org

The Asia Pacific Hospice Palliative Care Network was established to empower, and support individuals and organizations committed to alleviating suffering from life-threatening illness in the Asia Pacific region.

Association for Death Education & Counselling

www.adec.org

The Association for Death Education and Counseling is a professional organization dedicated to promoting excellence and recognizing diversity in death education, care of the dying, grief counseling and research in thanatology.

Canadian Hospice Palliative Care Association

www.chpca.net

The Canadian Hospice Palliative Care Association is the national association that provides leadership in hospice palliative care in Canada.

Centre to Advance Palliative Care

www.capc.org

The Centre to Advance Palliative Care (CAPC) provides health-care professionals with the tools, training and technical assistance necessary to start and sustain successful palliative care programmes in hospitals and other health-care settings.

Cicely Saunders International

www.cicelysaundersfoundation.org

Cicely Saunders International focuses on carrying out quality research to improve the care and treatment of all patients with progressive illness and to make high-quality palliative care available to everyone who needs it.

Elisabeth Kubler-Ross Foundation

www.ekrfoundation.org

The EKR Foundation is a non-profit organization inspired by the life of psychiatrist, humanitarian, and hospice pioneer Dr. Elisabeth Kübler-Ross. Chapters worldwide work to help develop palliative care in their countries.

European Association for Palliative Care

<https://www.eapcnet.eu/>

The aim of the EAPC is to promote palliative care in Europe and to act as a focus for all of those who work, or have an interest, in the field of palliative care at the scientific, clinical and social levels.

Hospice Foundation of America

www.hospicefoundation.org

Promotes education on death, dying, and bereavement through publications and teleconferences.

Hospice and Palliative Nurses Association

www.hpna.org

A membership association for nurses working in hospice and palliative care; offers national boards for certification of hospice nurses.

International Association for Hospice and Palliative Care

www.hospicecare.com

Our mission is to collaborate and work to improve the quality of life of patients with advanced life-threatening conditions and their families, by advancing hospice and palliative care programmes, education, research, and favourable policies around the world.

International Children's Palliative Care Network

<http://www.icpcn.org.uk/>

The International Children's Palliative Care Network (ICPCN) is a worldwide network of individuals and agencies working with children and young people with life-limiting conditions.

Latin American Association for Palliative Care

www.cuidadospaliativos.org

Our mission is to promote the development of palliative care in Latin America and the Caribbean, through its communication and integration of all stakeholders in improving the quality of life of patients with progressive incurable diseases and their families.

National Hospice Foundation

www.nationalhospicefoundation.org

The national charity for end of life care in the United States.

National Hospice and Palliative Care Organization

www.nhpc.org

NHPCO is the largest non-profit membership organization representing hospice and palliative care programmes and professionals in the United States.

National Palliative Care Research Centre

www.npcrc.org

The National Palliative Care Research Centre (NPCRC) is committed to stimulating, developing, and funding research directed at improving care for seriously ill patients and their families.

Palliative Care in Humanitarian Aid Situations and Emergencies Network

<https://www.phpc.cam.ac.uk/pcu/palchase/>

Palliative Care Australia

<https://palliativecare.org.au/>

Palliative Care Australia is the national peak body for palliative care. Working closely with consumers, our Member Organisations and the palliative care workforce, we aim to improve access to, and promote the need for, palliative care.

St. Christopher's Hospice

www.stchristophers.org.uk

The first modern hospice; St Christopher's exists to promote and provide skilled and compassionate palliative care of the highest quality.

Worldwide Hospice Palliative Care Alliance

www.thewhpc.org

The Worldwide Palliative Care Alliance (WPCA) is a global action network focusing exclusively on hospice and palliative care development worldwide. Its members are national and regional hospice and palliative care organizations and affiliate organizations supporting hospice and palliative care.

JOURNALS**American Journal of Hospice & Palliative Medicine**

Thousand Oaks, California: Sage Publications – Impact Factor 1.638

<http://ajh.sagepub.com/>

Annals of Palliative Medicine (APM)

AME Publishing Company. Hong Kong – Impact Factor – 1.681

<http://apm.amegroups.com>

BMC Palliative Care

Springer Nature. – Impact Factor 2.65

<https://bmc-palliativecare.biomedcentral.com>

BMJ Palliative and Supportive Care

London, England: BMJ Publishing Group – Impact Factor 2.681

<https://spcare.bmj.com/>

Death Studies

New York: Routledge – Impact Factor 1.361

<https://www.tandfonline.com/toc/udst20/current>

European Journal of Palliative Care

Newmarket, England

www.ejpc.eu.com

Indian Journal of Palliative Care

Wolters Kluwer, Netherlands – Impact Factor 1.0

<http://www.jpalliativecare.com/>

International Journal of Palliative Nursing

Mark Allen Group, London, UK – Impact Factor 0.91

<https://www.magonlinelibrary.com/toc/ijpn/current>

Journal of Hospice & Palliative Nursing

Wolters Kluwer, Netherlands – Impact Factor 0.877

<https://journals.lww.com/jhpn/pages/default.aspx>

Journal of Pain & Palliative Care Pharmacotherapy

Philadelphia, PA: The Taylor and Francis Group, Hayworth Press –

Impact Factor 0.96

<https://www.tandfonline.com/action/journalInformation?journalCode=izzp20>

Journal of Pain and Symptom Management

New York: Elsevier – Impact Factor 3.249

www.elsevier.com/wps/find/journaldescription.cws_home/505775/description#description

Journal of Palliative Medicine

New Rochelle, NY: Mary Ann Leibert – Impact Factor 2.085

<https://home.liebertpub.com/publications/journal-of-palliative-medicine/41>

Journal of Palliative Care

Sage Publications, Newbury Park, California – Impact Factor 1.2

<https://journals.sagepub.com/home/pal>

OMEGA: The Journal of Death & Dying

Sage Publications, Newbury Park, California – Impact Factor 1.347

<https://journals.sagepub.com/home/ome>

Palliative and Supportive Care

New York: Cambridge University Press – Impact Factor 1.968

<http://journals.cambridge.org/action/displayJournal?jid=PAX>

Palliative Medicine

London, England: Sage Publications – Impact Factor 3.739

www.sagepub.co.uk/journalsProdDesc.nav?prodId=Journal201823

APPENDIX 3

WHO Collaborating Centres on Palliative Care

- 1. WHO Collaborating Centre for Public Health Palliative Care Programmes**
Department of Palliative Care, Catalan Institute of Oncology
Institut Catala D'oncologia, Departament De Salut
Gran Via de l'Hospitalet 199-203, 08908, Catalonia, Barcelona Spain
Director: Dr Xavier Gomez-Batiste
Website: www.iconcologia.net
- 2. WHO Collaborating Centre for Community Participation in Palliative Care and Long-Term Care**
Institute of Palliative Medicine
Institute of Palliative Medicine, Medical College, 673008, Kerala, Kozhikode, India
Director: Dr Suresh Kumar
Website: www.instituteofpalliativemedicine.org
- 3. WHO Collaborating Centre for Palliative Care Policy and Rehabilitation**
King's College London
Cicely Saunders Institute, Bessemer Road SE5 9PJ
London, United Kingdom
Director: Dr Richard Harding
Website: <http://www.csi.kcl.ac.uk>
- 4. WHO Collaborating Centre for Training in Hospice & Palliative Care**
Research Institute for Hospice/Palliative Care, College of Nursing
The Catholic University of Korea, College of Nursing
222 Banpo-dearo, Seocho-gu 06591, Seoul, Republic of Korea
Director: Prof. Gyungyoo Lee kjdooly@catholic.ac.kr
Website: <http://hospice.catholic.ac.kr/english>
- 5. WHO Collaborating Centre for Training and Policy ion Access to Pain Relief**
Trivandrum Institute of Palliative Sciences
Manacaud PO, Paruthikkuzhy, Thiruvananthapuram
Trivandrum, India
Director: Dr M.R. Rajagopal, chairman@palliumindia.org
Website: <http://www.tipsindia.org/>
- 6. WHO Collaborating Centre for Cancer Control & Prevention**
National Cancer Centre
111 Jungbalsan-ro, Ilsangdong-gu, 410-769, Gyeonggi-do
Goyang, Republic of Korea
Director: Dr Eun Sook Lee eslee@ncc.re.kr & Mr Jong Soo Han hjs@ncc.re.kr
Website: <http://www.ncc.re.kr>

APPENDIX 4 Palliative Care cost-effectiveness literature summary

A total of 18 articles were reviewed. Overall, the utilization of both hospital-based and in-home hospice and palliative care services significantly reduced the cost of care, while providing equal if not better-quality care. In the reviewed studies, cost savings were attributed to reductions in the use of medical services, reductions in overall hospital costs, reductions in laboratory and intensive care unit costs, and significant decreases in hospital admissions, nursing home admissions, emergency department visits, and use of outpatient consultation services. The savings were particularly noticeable for Medicare expenditures. The savings were the highest among enrollees with lung cancer and other types of very aggressive cancer, with savings ranging from 7 to 17%. Taylor Jr. et al. (2007) observed that hospice use in the Medicare programme reduced expenditures by an average of \$2309 per hospice user in the last year of life.¹¹¹ Of particular significance, Pyenson et al. (2004) discovered that lower cost of care was not associated with shorter time until death.¹¹² On the contrary, lower cost of care appeared to be associated with longer mean time until death. Thus, developing palliative and hospice care programmes may carry both a “cost and quality incentive” for health-care providers and organizations.¹¹³

Only one study (Campbell et al., 2004)¹¹⁴ did find increased expenditures among some types of hospice users. In particular, the authors found increased expenditures among enrollees without cancer and those older than 84 years of age. However, the authors attributed this finding to the “trajectories to death” of conditions such as dementia and organ system failures. In other words, diseases such as cancer typically have a more predictable time frame for decline and death. Diseases such as dementia and organ system failure may not have such a predictable prognosis; consequently, providers may be “unable or unwilling to determine or accept a six-month prognosis or to forgo curative treatment for their terminal illness.” The authors suggest that facilitating earlier entry into hospice care in the non-cancer cohort may be a way to reduce the added costs associated with hospice care found in this study.

Two studies also examined the effect of end of life discussions on cost of care.¹¹⁵ Wright et al. (2008) found that having end of life discussions with physicians was associated with pursuing less aggressive medical care and having earlier referrals to hospice. Furthermore, the authors found that more aggressive care was associated with worse patient quality of life, as well as poorer caregiver bereavement adjustment.

A recent review article on the cost-effectiveness of palliative care has added to these findings. Smith et al.¹¹⁷ reviewed 46 articles and found palliative care to be less costly relative to comparator groups and a new study (2020) from Taiwan using national data on cancer mortality comparing hospice care to usual care found significant savings for hospice care.¹¹⁸ Palliative Care Australia has released a KPMG summary of the economics of increased investment in palliative care demonstrating 12% overall savings to health systems.¹¹⁹ While ethics precludes the random assignment of patients to non-hospice conditions, limiting the use of gold standard research, the body of evidence for the cost effectiveness of hospice and palliative care continues to grow.

APPENDIX 5 **World Health Assembly Resolution on Palliative Care**

SIXTY-SEVENTH WORLD HEALTH ASSEMBLY

WHA67.19

Agenda item 15.5

24 May 2014

Strengthening of palliative care as a component of comprehensive care throughout the life course

The Sixty-seventh World Health Assembly,

Having considered the report on strengthening of palliative care as a component of integrated treatment throughout the life course;¹

Recalling resolution WHA58.22 on cancer prevention and control, especially as it relates to palliative care;

Taking into account the United Nations Economic and Social Council's Commission on Narcotic Drugs' resolutions 53/4 and 54/6 respectively on promoting adequate availability of internationally controlled licit drugs for medical and scientific purposes while preventing their diversion and abuse, and promoting adequate availability of internationally controlled narcotic drugs and psychotropic substances for medical and scientific purposes while preventing their diversion and abuse;

Acknowledging the special report of the International Narcotics Control Board on the availability of internationally controlled drugs: ensuring adequate access for medical and scientific purposes,² and the WHO guidance on ensuring balance in national policies on controlled substances: guidance for availability and accessibility of controlled medicines;³

Also taking into account resolution 2005/25 of the United Nations Economic and Social Council on treatment of pain using opioid analgesics;

Bearing in mind that palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual;

Recognizing that palliative care, when indicated, is fundamental to improving the quality of life, well-being, comfort and human dignity for individuals, being an effective person-centred health service that values patients' need to receive adequate, personally and culturally sensitive information on their health status, and their central role in making decisions about the treatment received;

¹ Document 67/31.

² Document E/INCB/2010/1/Supp.1.

³ Ensuring balance in national policies on controlled substances: guidance for availability and accessibility of controlled medicines. Geneva: World Health Organization; 2011.

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Affirming that access to palliative care and to essential medicines for medical and scientific purposes manufactured from controlled substances, including opioid analgesics such as morphine, in line with the three United Nations international drug control conventions,¹ contributes to the realization of the right to the enjoyment of the highest attainable standard of health and well-being;

Acknowledging that palliative care is an ethical responsibility of health systems, and that it is the ethical duty of health care professionals to alleviate pain and suffering, whether physical, psychosocial or spiritual, irrespective of whether the disease or condition can be cured, and that end-of-life care for individuals is among the critical components of palliative care;

Recognizing that more than 40 million people currently require palliative care every year, foreseeing the increased need for palliative care with ageing populations and the rise of noncommunicable and other chronic diseases worldwide, considering the importance of palliative care for children, and, in respect of this, acknowledging that Member States should have estimates of the quantities of the internationally controlled medicines needed, including medicines in paediatric formulations;

Realizing the urgent need to include palliation across the continuum of care, especially at the primary care level, recognizing that inadequate integration of palliative care into health and social care systems is a major contributing factor to the lack of equitable access to such care;

Noting that the availability and appropriate use of internationally controlled medicines for medical and scientific purposes, particularly for the relief of pain and suffering, remains insufficient in many countries, and highlighting the need for Member States, with the support of the WHO Secretariat, the United Nations Office on Drugs and Crime and the International Narcotics Control Board, to ensure that efforts to prevent the diversion of narcotic drugs and psychotropic substances under international control pursuant to the United Nations international drug control conventions do not result in inappropriate regulatory barriers to medical access to such medicines;

Taking into account that the avoidable suffering of treatable symptoms is perpetuated by the lack of knowledge of palliative care, and highlighting the need for continuing education and adequate training for all hospital- and community-based health care providers and other caregivers, including nongovernmental organization workers and family members;

Recognizing the existence of diverse cost-effective and efficient palliative care models, acknowledging that palliative care uses an interdisciplinary approach to address the needs of patients and their families, and noting that the delivery of quality palliative care is most likely to be realized where strong networks exist between professional palliative care providers, support care providers (including spiritual support and counselling, as needed), volunteers and affected families, as well as between the community and providers of care for acute illness and the elderly;

Recognizing the need for palliative care across disease groups (noncommunicable diseases, and infectious diseases, including HIV and multidrug-resistant tuberculosis), and across all age groups;

¹ United Nations Single Convention on Narcotic Drugs, 1961, as amended by the 1972 Protocol; United Nations Convention on Psychotropic Substances, 1971; United Nations Convention against Illicit Traffic in Narcotic Drugs and Psychotropic Substances, 1988.

Welcoming the inclusion of palliative care in the definition of universal health coverage and emphasizing the need for health services to provide integrated palliative care in an equitable manner in order to address the needs of patients in the context of universal health coverage;

Recognizing the need for adequate funding mechanisms for palliative care programmes, including for medicines and medical products, especially in developing countries;

Welcoming the inclusion of palliative care actions and indicators in the WHO comprehensive global monitoring framework for the prevention and control of noncommunicable diseases and in the global action plan for the prevention and control of noncommunicable diseases 2013–2020;

Noting with appreciation the inclusion of medicines needed for pain and symptom control in palliative care settings in the 18th WHO Model List of Essential Medicines and the 4th WHO Model List of Essential Medicines for Children, and commending the efforts of WHO collaborating centres on pain and palliative care to improve access to palliative care;

Noting with appreciation the efforts of nongovernmental organizations and civil society in continuing to highlight the importance of palliative care, including adequate availability and appropriate use of internationally controlled substances for medical and scientific purposes, as set out in the United Nations international drug control conventions;

Recognizing the limited availability of palliative care services in much of the world and the great avoidable suffering for millions of patients and their families, and emphasizing the need to create or strengthen, as appropriate, health systems that include palliative care as an integral component of the treatment of people within the continuum of care,

1. URGES Member States:¹

- (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;
- (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;
- (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;
- (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:

¹ And, where applicable, regional economic integration organizations.

WHA67.19

- (a) 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 health care workers, caregivers addressing patients' spiritual needs and social workers;
 - (b) intermediate training should be offered to all health care workers who routinely work with patients with life-threatening illnesses, including those working in oncology, infectious diseases, paediatrics, geriatrics and internal medicine;
 - (c) specialist palliative care training should be available to prepare health care professionals who will manage integrated care for patients with more than routine symptom management needs;
- (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;
 - (6) to review and, where appropriate, revise national and local legislation and policies for controlled medicines, with reference to WHO policy guidance,¹ on improving access to and rational use of pain management medicines, in line with the United Nations international drug control conventions;
 - (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;
 - (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;
 - (9) to implement and monitor palliative care actions included in WHO's global action plan for the prevention and control of noncommunicable diseases 2013–2020;
2. REQUESTS the Director-General:
- (1) to ensure that palliative care is an integral component of all relevant global disease control and health system plans, including those relating to noncommunicable diseases and universal health coverage, as well as being included in country and regional cooperation plans;
 - (2) 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;
 - (3) 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

¹ Ensuring balance in national policies on controlled substances: guidance for availability and accessibility of controlled medicines. Geneva: World Health Organization; 2011.

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care, such as equitable access, person-centred and respectful care, and community involvement, and to inform education in pain and symptom management and psychosocial support;

(4) to continue, through WHO's Access to Controlled Medicines Programme, 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;

(5) to explore ways to increase the availability and accessibility of medicines used in palliative care through consultation with Member States and relevant networks and civil society, as well as other international stakeholders, as appropriate;

(6) 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;

(7) to further cooperate 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;¹

(8) to collaborate with UNICEF and other relevant partners in the promotion and implementation of palliative care for children;

(9) to monitor the global situation of palliative care, evaluating the progress made in different initiatives and programmes in collaboration with Member States and international partners;

(10) to work with Member States to encourage adequate funding and improved cooperation for palliative care programmes and research initiatives, in particular in resource-poor countries, in line with the Programme budget 2014–2015, which addresses palliative care;

(11) to encourage research on models of palliative care that are effective in low- and middle-income countries, taking into consideration good practices;

(12) to report back to the Sixty-ninth World Health Assembly in 2016 on progress in the implementation of this resolution.

Ninth plenary meeting, 24 May 2014
A67/VR/9

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