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Global Atlas of Palliative Care at the End of Life

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Table of contents

Acronyms 1

Forewords 2

Chapter 1 **Introduction** 4

What is palliative care for adults, for children? 5

The definition of palliative care 7

The relationship between curative and palliative care 8

Why is palliative care a human rights issue? 9

Chapter 2 **How many people at the end of life are in need of palliative care worldwide?** 10

Diseases requiring palliative care 10

Estimates based on the number of patients dying from cancer and other life-limiting conditions and the estimated number of family and healthcare givers 11

Maps depicting the overall palliative care needs by age (< 15 and >15 years of age) and gender 13

Maps and tables describing the need for palliative care at the end of life for adults 14

Maps and tables describing the need for palliative care at the end of life for children 19

Summary and conclusions 25

Chapter 3 **What are the main barriers to palliative care development?** 27

Based on policy, education, and opioid availability 27

Maps on opioid use by country 29

Psychological, social, cultural, and financial barriers 31

Palliative care for TB: a new and emerging issue 31

Chapter 4 **What is the response to address the needs and barriers to good quality palliative care?** 34

Maps showing levels of palliative care development by country 35

Map showing the availability of children's palliative care services 43

Maps showing numbers of palliative care-specific providers to base population 46

Chapter 5 **What are existing models of palliative care (including financial mechanisms) in different resource settings?**

Case studies of different models of care 47

Kerala, India 48

Arusha, Tanzania 50

Brasov, Romania 52

Ft. Myers, Florida, USA 54

Ho Chi Minh City, Vietnam 56

Buenos Aires, Argentina 58

Lichfield, England 60

Chapter 6 **What are the available resources at global/regional levels to support palliative care policies, programmes and research in low-middle income countries?** 62

Financial resources devoted to palliative care 62

Philanthropic and bilateral support 63

Research support 64

Educational resources 65

Chapter 7 **What is the way forward to advance palliative care in the health and human rights agendas at global/regional/country levels? And conclusions** 71

Appendix 1 **Methodology for a Global Atlas of Palliative Care at the End of Life** 76

Appendix 2 **Additional sections of the Mapping levels of Palliative Care Report** 78

Appendix 3 **Organisational resources** 84

Appendix 4 **WHO collaborating centres on palliative care** 90

Appendix 5 **Report on cost-effectiveness of palliative care** 91

Appendix 6 **Methodology for estimating the need for palliative care, including a country-by-country listing** 93

References 99

List of figures

1. Distribution of major causes of death worldwide (2011) 11
2. Distribution of people in need of palliative care at the end of life by age group 12
3. World map showing the global distribution by regions of rates for people in need of palliative care at the end of life 13
4. Distribution of adults in need of palliative care at the end of life by gender 13
5. Distribution of adults in need of palliative care at the end of life by disease groups 14
6. Distribution of adults in need of palliative care at the end of life by age and disease groups 14
7. Distribution of adults in need of palliative care at the end of life by WHO regions 15
8. Rates of adults in need of palliative care at the end of life by WHO region 15
9. Distribution of adults in need of palliative care at the end of life by WHO regions and disease categories 16
10. Distribution of adults in need of palliative care at the end of life by World Bank country income groups 16
11. Rates of adults in need of palliative care at the end of life by World Bank country income groups 17
12. World map showing the global distribution by WHO regions of rates for adults in need of palliative care at the end of life 17
13. World map showing the global distribution by regions of rates for adults in need of palliative care for cancer at the end of life 18
14. World map showing the global distribution by WHO regions of rates for adults in need of palliative care for HIV/AIDS at the end of life 18
15. World map showing the global distribution by WHO regions of rates for adults in need of palliative care for progressive non-malignant disease at the end of life 19
16. Distribution of children in need of palliative care at the end of life by gender 19
17. Distribution of children in need of palliative care at the end of life by disease groups 20
18. Distribution of children in need of palliative care at the end of life by WHO regions 20

19. Rates of children in need of palliative care at the end of life by WHO regions 21
20. Distribution of children in need of palliative care at the end of life by WHO regions and disease categories 21
21. Distribution of children in need of palliative care at the end of life World Bank country income groups 22
22. Rates of children in need of palliative care at the end of life by World Bank country income groups 22
23. World map showing the global distribution by regions of rates for children in need of palliative care at the end of life 23
24. World map showing the global distribution by WHO regions of rates for children in need of palliative care for cancer at the end of life 23
25. World map showing the global distribution by WHO regions of rates for children in need of palliative care for HIV/AIDS at the end of life 24
26. World map showing the global distribution by regions of rates for children in need of palliative care for progressive non-malignant diseases at the end of life 24
27. Morphine use worldwide 29
28. Morphine equivalent total opioid use worldwide 29
29. Public health model for palliative care development 30
30. World map showing the global mortality rates for tuberculosis including HIV-positive for all ages 32
31. Countries with no known hospice/palliative care activity (Level 1) 35
32. Countries with capacity building activity (Level 2) 36
33. Countries with isolated provision of palliative care (Level 3a) 38
34. Countries with generalised provision of palliative care (Level 3b) 38
35. Countries with preliminary health system integration (Level 4a) 40
36. Countries with advanced health system integration (Level 4b) 40
37. Levels of palliative care development – all countries 42
38. Levels of paediatric palliative care development – all countries 43
39. Services/providers to base population (per 1M population) 46
40. Estimated number of patients receiving palliative care 46

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
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
SEARO	Southeast Asian Region of the World Health Organization
UN	United Nations
UNICEF	United Nations Children's Fund
WHO	World Health Organization
WPCA	Worldwide Palliative Care Alliance
WPRO	Western Pacific Region of the World Health Organization

Foreword

Palliative care, while still a relatively new component to modern healthcare, is increasingly recognised as an essential part of all healthcare systems. Despite this, it is widely acknowledged that there is still inadequate access to hospice and palliative care worldwide, and with an ageing population who are going to be living and dying with more complex conditions, the demand for care is only going to increase.

Now, for the first time, we have a resource that attempts to quantify the need for and availability of palliative care worldwide.

It is important to acknowledge that, while the atlas focuses on the need of patients at the end of life, many more people early in their course of illness, as well as family members and carers, could also benefit from palliative care, and therefore the real need is much greater.

Historically, hospice and palliative care programmes have focused on the needs of cancer patients known to have high symptom burdens. However, the majority of those needing palliative care worldwide suffer from non-malignant conditions, which are defined in this atlas. We hope we can encourage countries to ensure that efforts to expand palliative care include these patients with other life-threatening illnesses who also suffer during their treatment, illness, and end of life.

WHO has focused in recent years on HIV/AIDS, tuberculosis and other infectious diseases and now has a major initiative to address the burdens of non-communicable disease. Palliative care is needed for these conditions, but what is also needed is for the global community to work together to help prevent early mortality from communicable and non-communicable diseases. Palliative care, while vital at the end of life, also has a key role to play in this prevention.

Our efforts to expand palliative care need to focus on bringing relief of suffering and the benefits of palliative care to those with the least resources. This will take courage and creativity as we learn from each other how to integrate palliative care into existing but very limited healthcare systems.

This global atlas shines a light on the need for palliative care globally, and serves as a baseline, against which to make measurements, in order to advocate for increased access.

Cynthia Goh, MD Co-Chair WPCA

David Praill, Co-Chair WPCA

Foreword

The WHO, together with its partners, is working on the implementation of the Global Action Plan for the Prevention and Control of Noncommunicable Diseases 2013-2020. While we join efforts to reduce the burden of the biggest killers in the world today, we must also alleviate the suffering of those with progressive illnesses so their quality of life is improved. This joint WHO-WPCA publication is an outstanding example of collaborative effort to position palliative care higher in the global and national health agendas. The great majority of palliative care need is associated with noncommunicable diseases.

The *Global Atlas of Palliative Care at the End of Life* is an excellent tool to advocate for the inclusion of palliative care in the global, regional and national health agendas. In its Chapter 2, WHO provides for the first time quantitative estimates on the need of palliative care for adults and children. Each year around 20 million people need end of life palliative care, including 6% that are children. These are low level estimates because around 20 million more require palliative care in the years before death. The numbers are huge and so is the unmet need as only a few countries have implemented equitable palliative care programs through a public health approach. Moreover, in many countries opioid analgesics are not available or accessible to the majority of patients suffering moderate or severe pain.

In January 2014 the WHO Executive Board will address the need for taking global and national action for the integration of palliative care into health systems. A group of Member States is supporting this initiative and the WHO secretariat has developed a comprehensive report that includes the global estimates. Thus the publication of the Global Atlas comes at a very timely moment. It not only provides evidence on the needs across various disease groups and conditions in adults and children, but also analyses models that work in different resource settings and stimulates urgent action. We are certain that this comprehensive information will be very useful for the executive board members when taking a decision on how to move this agenda forward.

WHO will continue collaborating with WPCA and other partners to support countries in their efforts to develop palliative care policies and services and to ensure that the majority of the patients get the care they need even in limited resource settings.

Dr Oleg Chestnov
Assistant Director General
Noncommunicable Diseases and Mental Health

Chapter 1 Introduction

The need for palliative care has never been greater and is increasing at a rapid pace due to the world's ageing population and increases in cancer and other noncommunicable diseases. Despite this need, palliative care is underdeveloped in most of the world, and outside North America, Europe, and Australia, access to quality palliative care is very rare. Palliative care is expanding in the developed world in spite of myths and misunderstanding about its nature and purpose, but is only beginning to be available in the developing world where it is needed most.

Since the early 1980s, the need for palliative care for cancer patients 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/AIDS, congestive heart failure, cerebrovascular disease, neurodegenerative disorders, chronic respiratory diseases, drug-resistant tuberculosis, 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 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?
- Why is palliative care a human rights issue?
- What are the main diseases requiring palliative care?
- What is the need for palliative care?
- What are the barriers to palliative care?
- 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 Organization established a revised definition of palliative care for adults and a separate one for children:

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

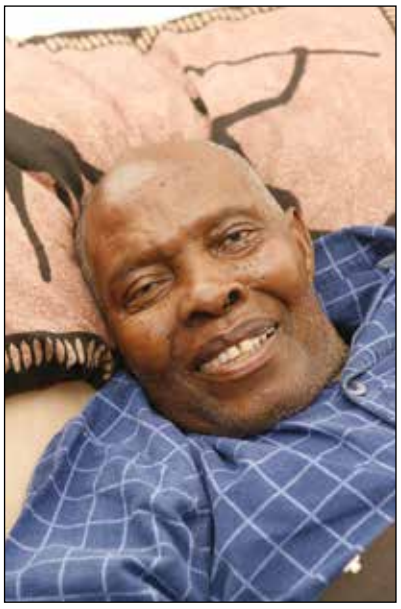
WHO definition of palliative care for children

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.[1]

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 Hospice[2] – 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.



The definition of palliative care

The Global Atlas adopts the current World Health Organization definition of palliative care. However, it has been recognised for some years that this definition requires further explanation to clarify the comprehensive nature of palliative care (WPCA Policy statement on defining palliative care)[3]. We elucidate this here, with supporting evidence, to ensure the definition is more explicit and transparent.

First, ***palliative care is needed in chronic as well as life-threatening/limiting-conditions***.

- Adults with a wide range of chronic conditions throughout the world have been recognised as benefiting from palliative care[4,5,6,7,8]. Early intervention, well before the terminal stage, is recognised as optimal[9,10].
- The WHO definition of palliative care for children states that palliative care should be provided to children with chronic and life-limiting illness, not only those who are dying. Paediatric palliative care begins when the illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.

Second, ***there is no time or prognostic limit on the delivery of palliative care***.

- It has been widely advocated that palliative care should be delivered on the basis of need, not diagnosis or prognosis[11,12,13,14].
- Although we have estimated numbers based on mortality data for consistency, palliative care should be provided 'early in the course of the illness' (WHO definition of palliative care) and at least as many people are estimated to have palliative care needs before the last year of life as during the last year of life.

Third, ***the Global Atlas describes the need for palliative care at all levels of care.***

- Palliative care is not limited to specialist palliative care services but includes primary and secondary level care.
- Palliative care is provided at three different levels: i) through a 'palliative care approach' adopted by all healthcare professionals, provided they are educated and skilled through appropriate training ii) 'general palliative care' provided by primary care professionals and those treating patients with life-threatening diseases, with a good basic knowledge of palliative care, and iii) 'specialist palliative care' provided by specialised teams for patients with complex problems[15,16].

- The Global Atlas includes all three levels, and the requirement for provision at the three different levels will vary from country to country, depending on the proportion of deaths from palliative care diagnoses, according to models of healthcare, and the nature and extent of integration of palliative care within these models. In high income countries, it is estimated that between 30-45% of palliative care need may be met by specialist palliative care[17,18,19].

Fourth, ***palliative care is not limited to any one care setting***

- Palliative care is provided wherever a person's care takes place, whether this is the patient's own home, a care facility, hospice in-patient unit, hospital, or outpatient or day care service.

The relationship between curative and palliative care

The relationship between curative and palliative care plays out differently in different countries and societies, for a variety of reasons. However, we emphasise that palliative care should in no way become a substitute for appropriate curative care.

- Modern medical care has a strong bias towards curative medicine. In high income countries, death is frequently medicalised, and curative treatments may be prioritised ahead of palliative care[20]. Better, and earlier, integration of palliative care alongside active treatment is needed[9,10].
- For low and middle income countries, however, curative care and active management may be very limited, or not available at all. Palliative care is needed, but not as a substitute for development of healthcare systems and provision of appropriate services.
- In some societies, the cultural context may mean that death and dying are often stigmatised, such that perceptions and taboos need to be challenged before palliative care provision can be addressed[20].

The Worldwide Palliative Care Alliance recommends that all governments integrate palliative care into their country's health system[3], alongside curative care. At a minimum, palliative care should be provided even when curative care is unavailable[20].

Why is palliative care a human rights issue?

In a recent article, Brennan[21] argued that palliative care is a human right. The main argument centres on the International Human Right to Health from the International Covenant on Economic, Social and Cultural Rights (ICESCR) Article 12.1 (1966) calling for the "right of everyone to the enjoyment of the highest attainable standard of physical and mental health". This right is not enforceable except that signatory countries are expected to work toward its fulfillment.

While palliative care is not specifically mentioned in the statement, 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 medicines 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 a life-limiting illness should have access to appropriate healthcare, basic medications for symptom control and terminal care, as well as inclusion of palliative care in national healthcare policies. The UN Committee on Economic, Social and Cultural Rights reports 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"[22].

Access to essential medicines, as defined by the WHO Action Programme on Essential Medicines, is part of the minimum core content of the right to the highest attainable standard of health.[23] Fourteen palliative care medications are currently on the WHO Essential Drug List.

The UN Special Rapporteur on torture has said that denying access to pain relief can amount to inhuman and degrading treatment. In addition many international organisations and bodies have called for the provision of palliative care as an essential component of healthcare including the WHO, the Senate of Canada (2000),[24] the European Committee of Ministers (2003),[25] the European School of Oncology (2004)[26], the WPCA (2005), and Human Rights Watch (2012).[27,28]

Chapter 2

How many people at the end of life are in need of palliative care worldwide?

Assessing palliative care needs is in many ways equivalent to assessing an urgent humanitarian need to reduce unnecessary suffering of patients and their families. It is important to bear in mind that although – in the medium to long term – effective prevention, early detection and treatment will reduce palliative care needs, palliative care needs will never be eliminated, because some types of cancer and other chronic diseases will inevitably remain fatal for some patients.[29]

The methodology used for estimating the people in need of palliative care at the end of life worldwide is based on the framework described in a previous palliative care publication by WHO. This framework considers mortality data from diseases requiring palliative care adjusted by the estimated pain prevalence for each disease category (cancer, HIV/AIDS and progressive non-malignant diseases) as described by Higginson, 1997.[30] Detailed description is provided in Appendix 6.

Diseases requiring palliative care

Mortality data was obtained from the *WHO Global Health Estimates* for 2011[31]. The diseases of adults (population aged 15 years and above) and children (population under age 15) requiring palliative care were identified through respective Delphi studies and subsequent internal reviews (see Appendix 6 for further details).

- *Diseases requiring palliative care for adults:* Alzheimer's and other dementias, cancer, cardiovascular diseases (excluding sudden deaths), cirrhosis of the liver, chronic obstructive pulmonary diseases, diabetes, HIV/AIDS, kidney failure, multiple sclerosis, Parkinson's disease, rheumatoid arthritis, drug-resistant tuberculosis (TB).
- *Diseases requiring palliative care for children:* cancer, cardiovascular diseases, cirrhosis of the liver, congenital anomalies (excluding heart abnormalities), blood and immune disorders, HIV/AIDS, meningitis, kidney diseases, neurological disorders and neonatal conditions.

Pain prevalence

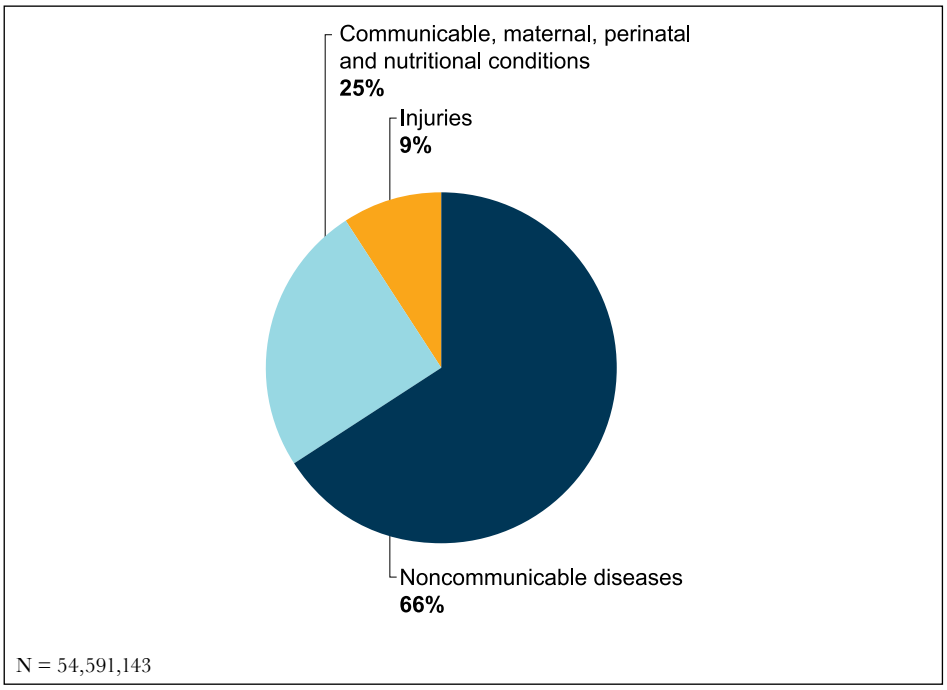
Not all the people dying from these diseases will require palliative care, therefore the prevalence of pain, one of the most common symptoms in people dying from both malignant and non-malignant chronic conditions, has been used as an indicator of the need for palliative care services at the end of life.

Therefore, the estimates of palliative care needs described in this chapter are lower level estimates as they refer to end of life care. If we consider that for every adult or child dying from a disease requiring palliative care, there is at least one or two caregivers involved, the total number of people in need of palliative care would double or triple. These estimates also do not include those needing palliative care prior to their last year of life nor do they include orphans, vulnerable children, or the bereaved.

Estimates of people in need of palliative care at the end of life worldwide[32]

According to *WHO Global Health Estimates* there were approximately 54.6 million deaths worldwide in 2011. The great majority of deaths, 66%, are due to noncommunicable diseases (Fig. 1).

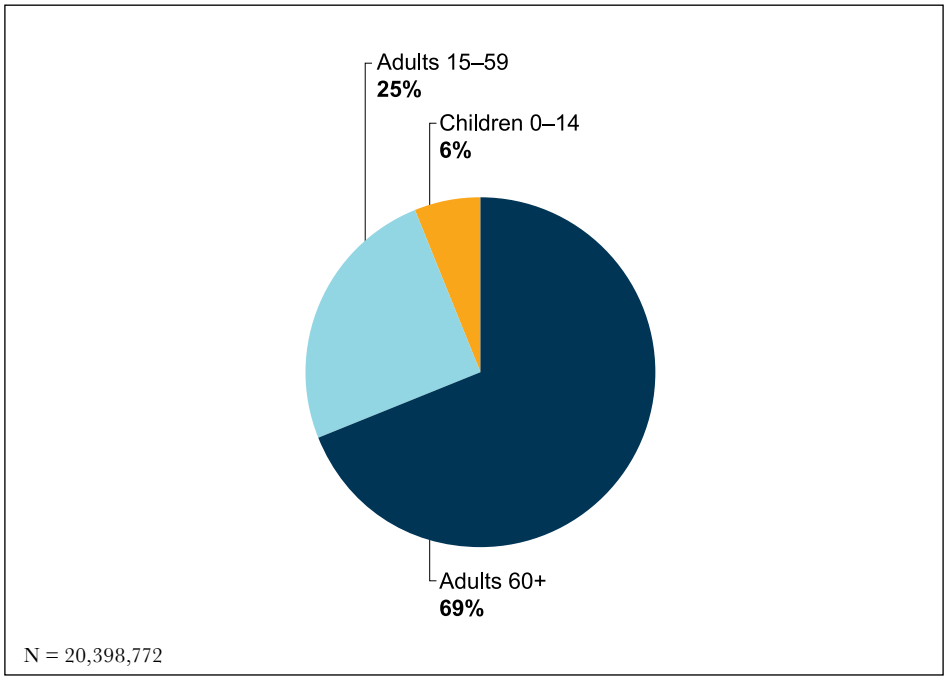
Figure 1
Distribution of major causes of death worldwide



Palliative care services focus mainly on noncommunicable causes of death in addition to other chronic conditions such as HIV/AIDS and drug-resistant TB.

Globally, in 2011, over 29 million (29,063,194) people died from diseases requiring palliative care. The estimated number of people in need of palliative care at the end of life is 20.4 million. The biggest proportion, 94%, corresponds to adults of which 69% are over 60 years old and 25% are 15 to 59 years old. Only 6% of all people in need of palliative care are children (Fig. 2).

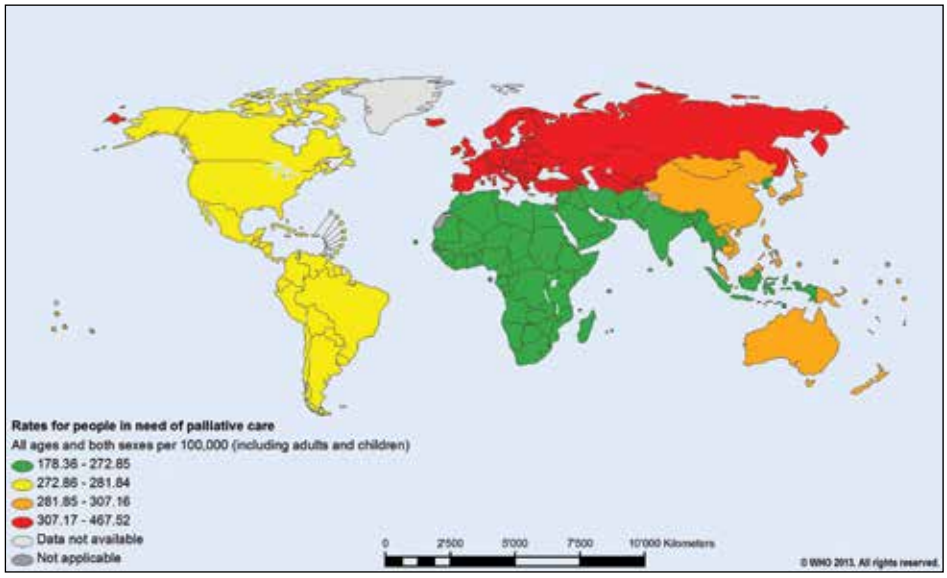
Figure 2
Distribution of people in need of palliative care at the end of life by age group



Based on these estimates, each year in the world, around 377 adults out of 100,000 population over 15 years old, and 63 children out of 100,000 population under 15 years old will require palliative care at the end of life.

WHO Member States are grouped in six regions: Region of the Americas (AMRO), African Region (AFRO), Eastern Mediterranean Region (EMRO), European Region (EURO), South East Asia Region (SEARO) and Western Pacific Region (WPRO). The world map showing the global distribution of rates for people in need of palliative care at the end of life (Fig. 3) indicates higher rates in the European and Western Pacific regions.

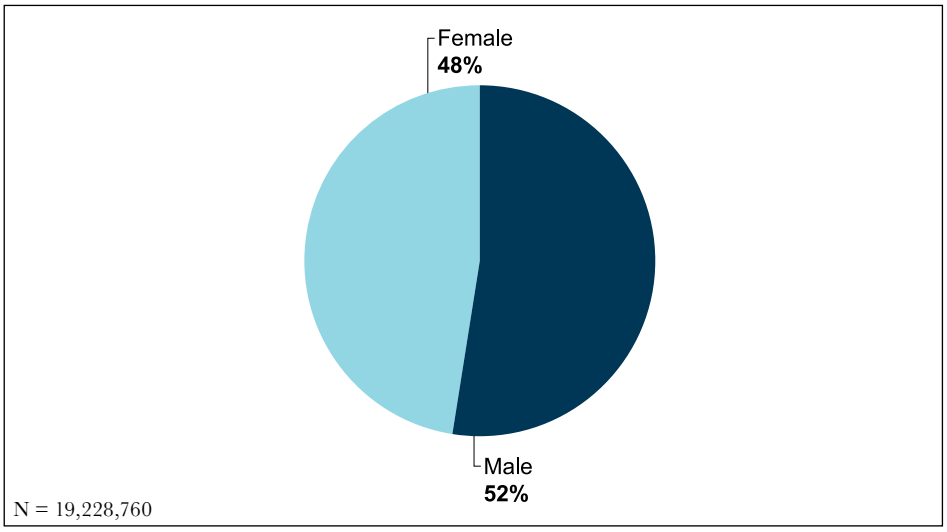
Figure 3
World map showing the global distribution by WHO regions of rates for people in need of palliative care at the end of life



Estimates of adults in need of palliative care at the end of life

The estimated global number of adults in need of palliative care at the end of life is over **19 million**. The majority, 69%, corresponds to older adults (Fig. 2) and there is a slight predominance of males (Fig. 4).

Figure 4
Distribution of adults in need of palliative care at the end of life by gender



The great majority of adults in need of palliative care died from cardiovascular diseases (38.5%), and cancer (34%), followed by chronic respiratory diseases (10.3%), HIV/AIDS (5.7%), and diabetes (4.5%) (Fig. 5). Those in need of palliative care dying from HIV/AIDS concentrate in the younger age group, 15 to 59; whereas those dying from Alzheimer's, Parkinson's, chronic respiratory diseases, cardiovascular diseases, diabetes, rheumatoid arthritis and cancer are predominantly in the older age group (Fig. 6).

Figure 5
Distribution of adults in need of palliative care at the end of life by disease groups

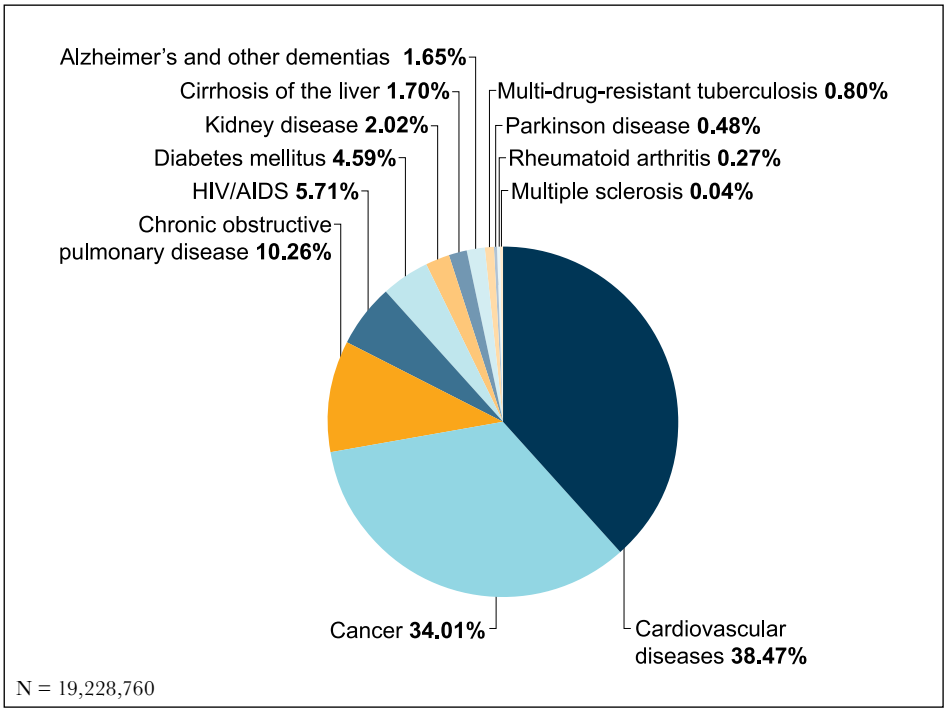
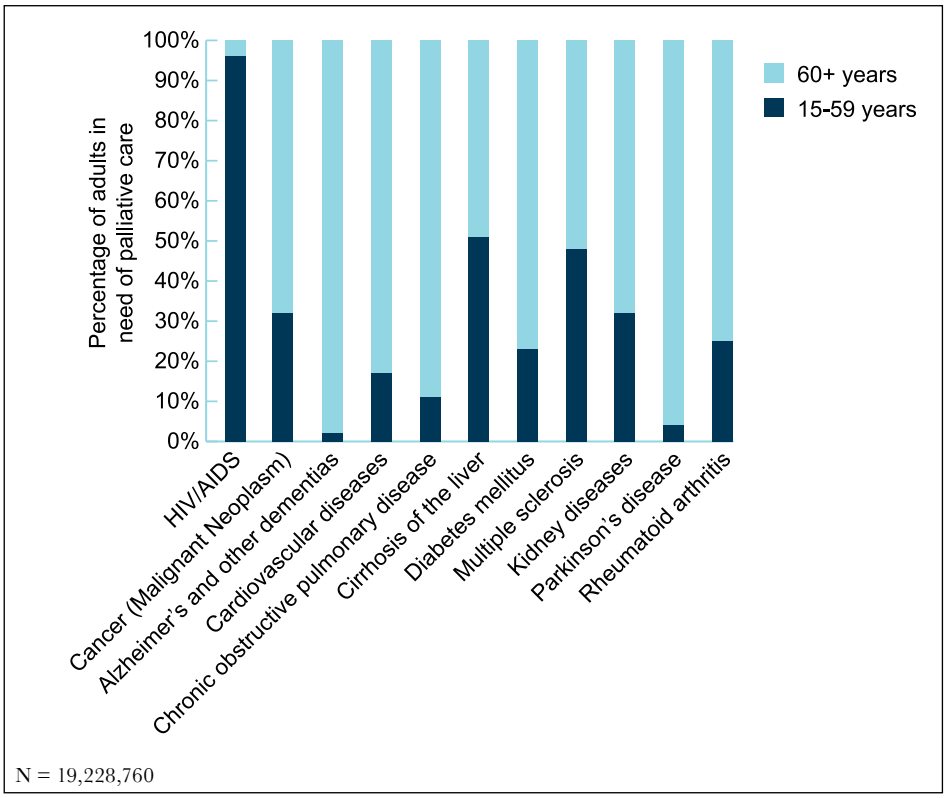


Figure 6
Distribution of adults in need of palliative care at the end of life by age and disease groups



The Western Pacific Region concentrates almost one-third of all cases (29%), followed by the European and Southeast Asia regions (22% each). The distribution in the Region of the Americas, African and Eastern Mediterranean regions is 13%, 9% and 5% respectively (Fig. 7). However, the European Region has the highest rate per 100,000 adult population, followed by Western Pacific Region, Region of the Americas and African Region.

Figure 7
Distribution of adults in need of palliative care at the end of life by WHO regions

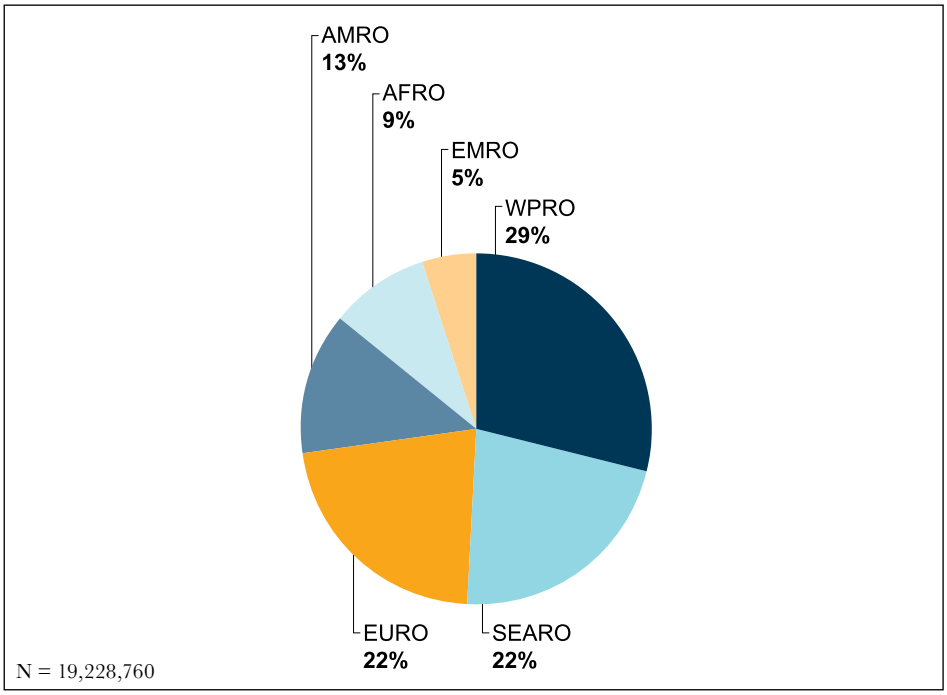
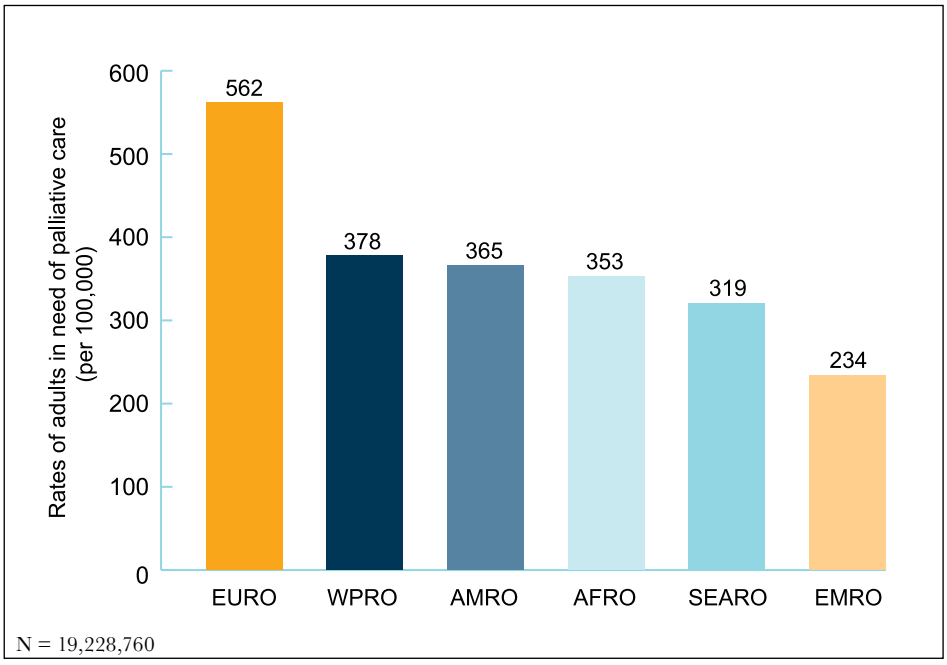
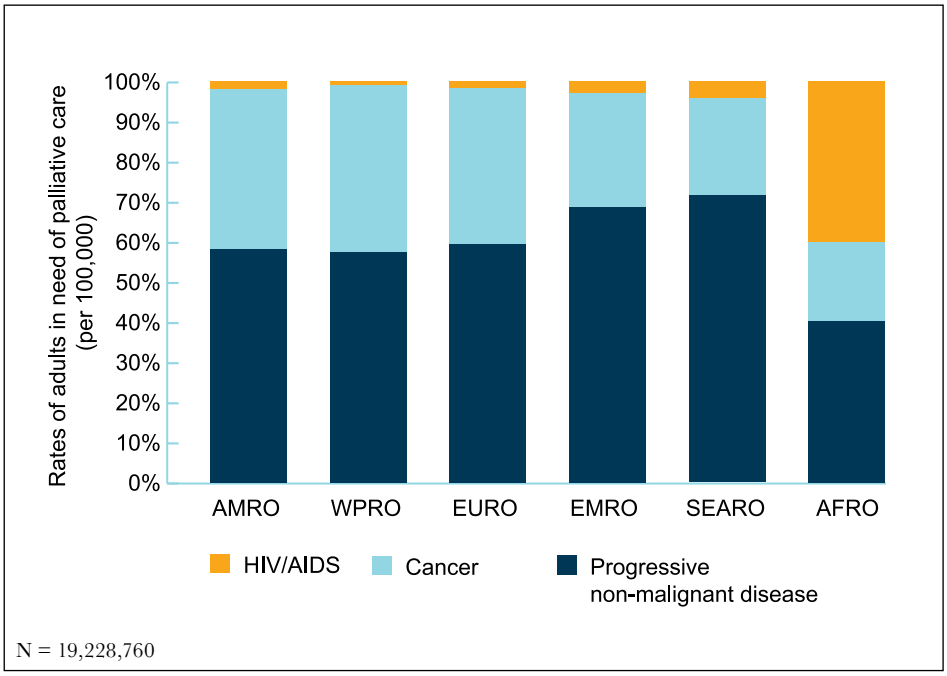


Figure 8
Rates of adults in need of palliative care at the end of life by WHO region



The diseases requiring palliative care at the end of life were grouped in three categories: cancer, HIV/AIDS, and progressive non-malignant diseases. In all regions, adults in need of palliative care for progressive non-malignant disease represent the highest proportion. HIV/AIDS predominates in the African Region. The proportion of adults in need of palliative care for cancer is relatively important for all regions. It ranges from 19.6% in the African Region to 41.5% in the Western Pacific Region (Fig. 9).

Figure 9
Distribution of adults in need of palliative care at the end of life by WHO regions and disease categories



The great majority, 78%, of adults in need of palliative care at the end of life belong to low and middle-income countries (Fig. 10). However, the highest rates per 100,000 adult population in need of palliative care are found in the higher income groups (Fig. 11).

Figure 10
Distribution of adults in need of palliative care at the end of life by World Bank country income groups

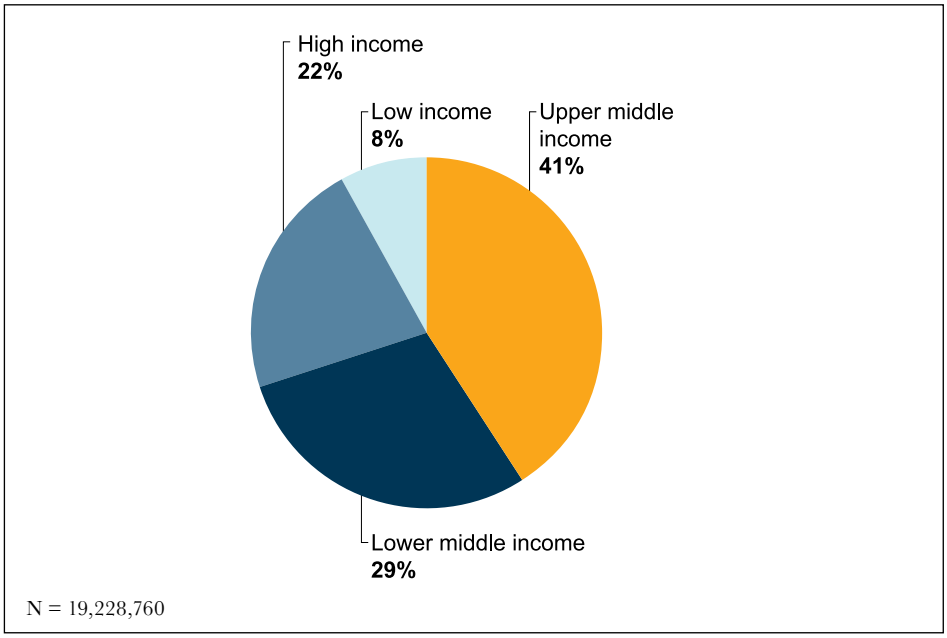
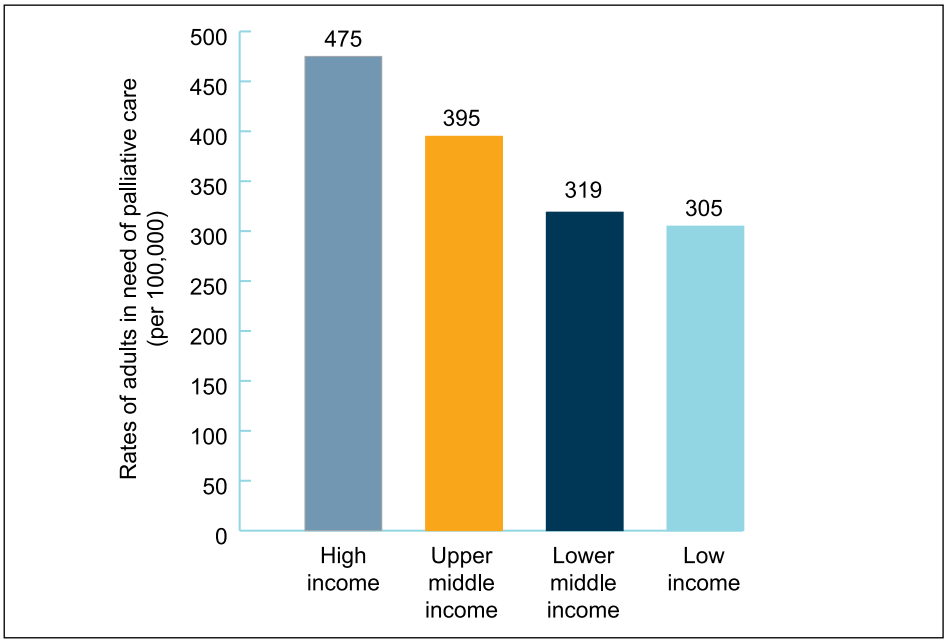


Figure 11
Rates of adults in need of palliative care at the end of life by World Bank country income groups



The world map showing the global distribution of rates of adults in need of palliative care at the end of life (Fig. 12) indicates higher rates in the European and Western Pacific regions. Figures 13 to 15 show rates for adults in need of palliative care at the end of life for each disease category, cancer, HIV/AIDS and progressive non-malignant diseases. The highest rates for adults in need of cancer palliative care (Fig. 13) are seen in the European and the Western Pacific regions. In the case of palliative care for HIV/AIDS, the highest rates are in the African and South East Asia regions (Fig. 14). The European and South East Asia regions have the highest rates of palliative care for progressive non-malignant diseases (Fig. 15).

Figure 12
World map showing the global distribution by WHO regions of rates for adults in need of palliative care at the end of life

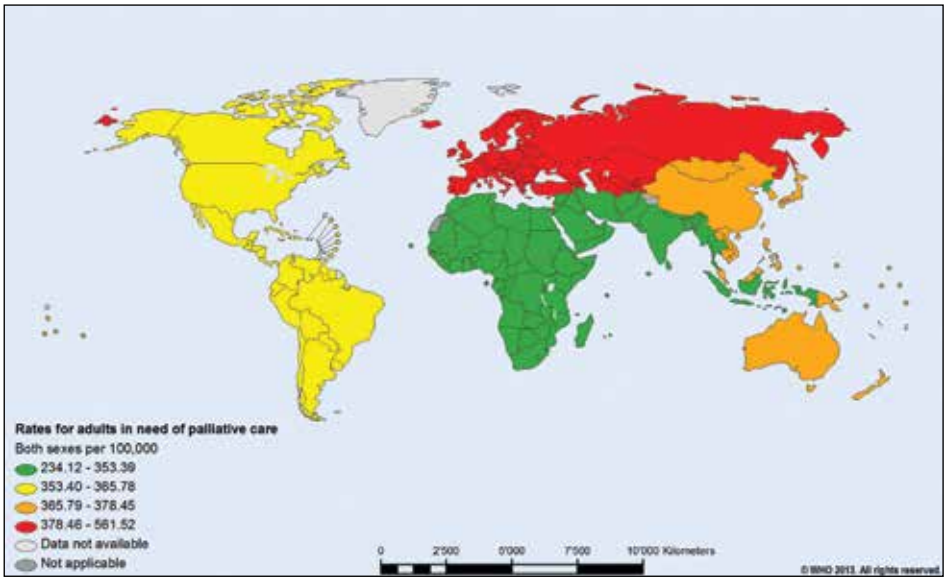


Figure 13
World map showing the global distribution by WHO regions of rates for adults in need of palliative care for **cancer** at the end of life

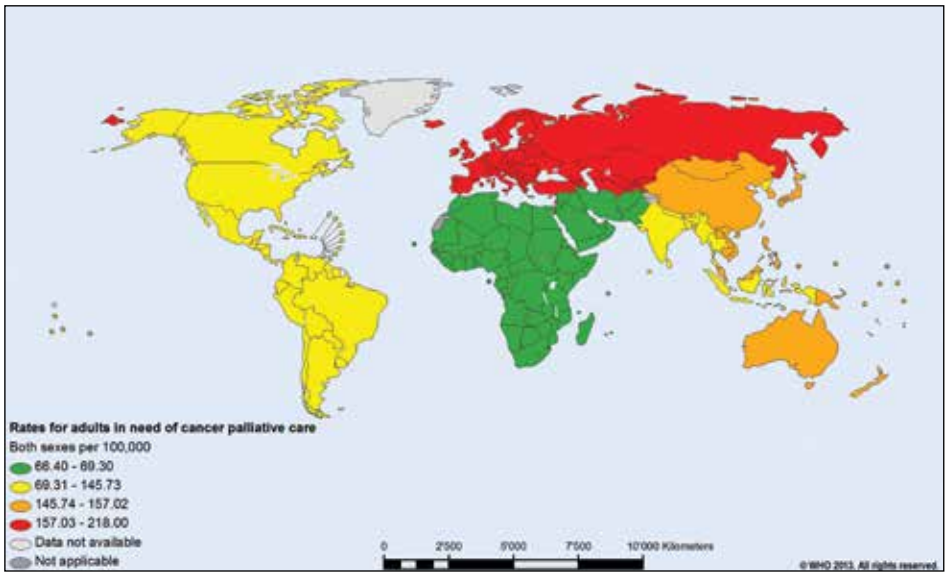


Figure 14
World map showing the global distribution by WHO regions of rates for adults in need of palliative care for **HIV/AIDS** at the end of life

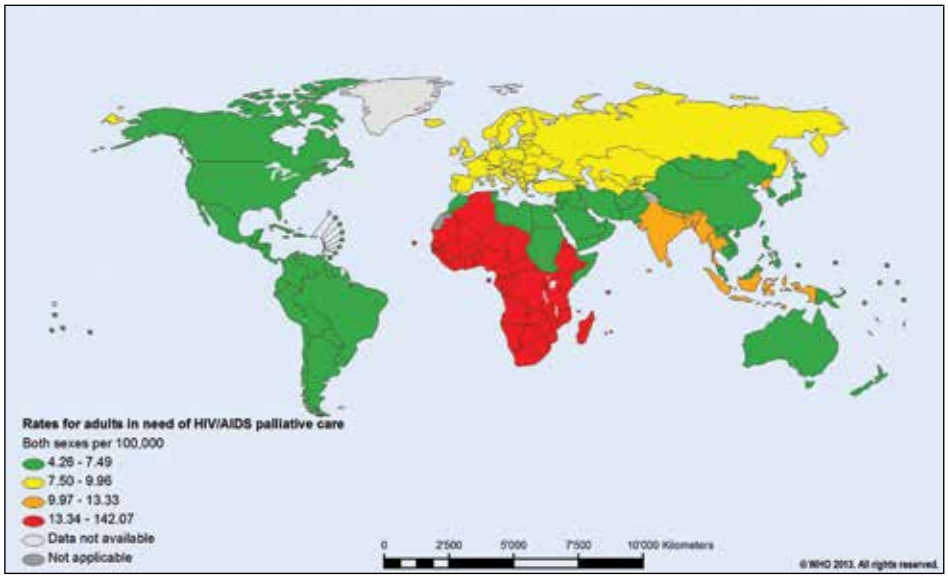
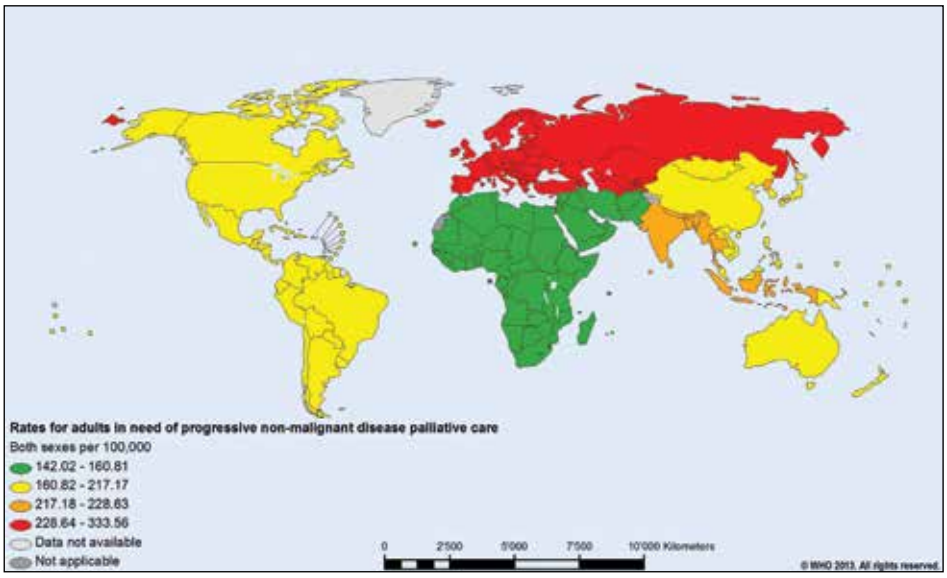


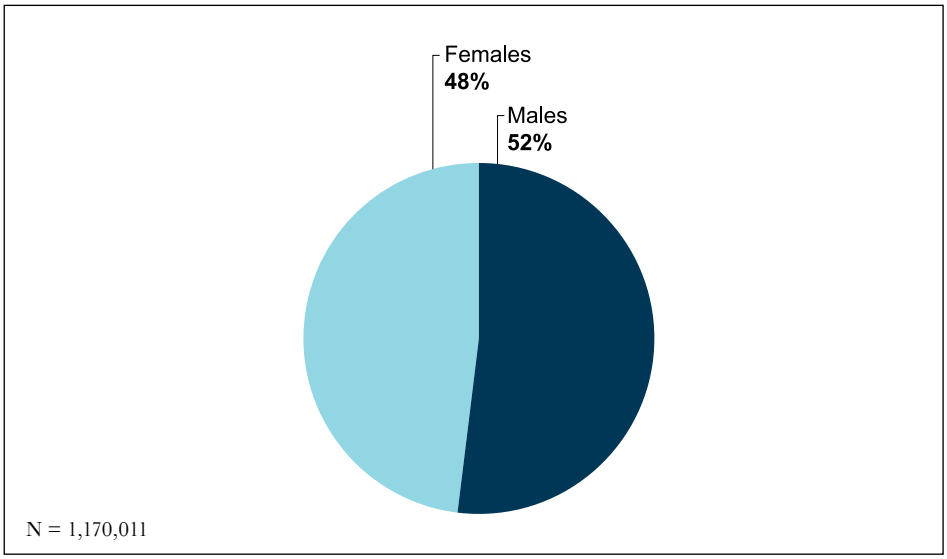
Figure 15
World map showing the global distribution by WHO regions of rates for adults in need of palliative care for **progressive non-malignant disease** at the end of life



Estimates of children in need of palliative care at the end of life worldwide

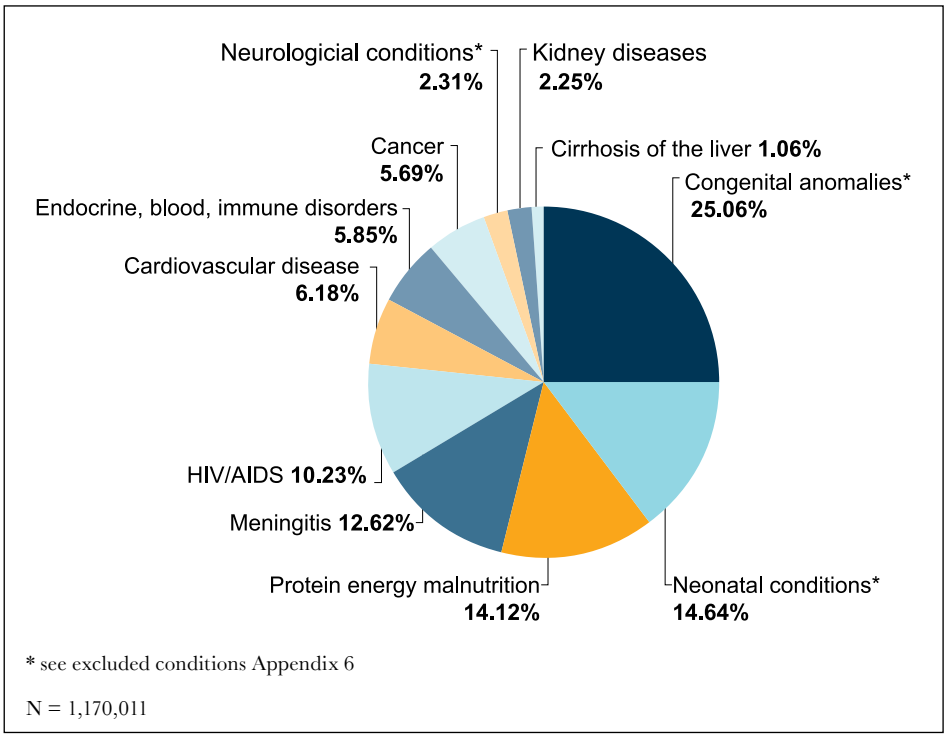
The estimated global number of children in need of palliative care at the end of life is almost 1.2 million. There is a slightly higher proportion of males than females (Fig. 16).

Figure 16
Distribution of children in need of palliative care at the end of life by gender



The greatest number of children in need of palliative care died from congenital anomalies, followed by neonatal conditions, protein energy malnutrition, meningitis, HIV/AIDS and cardiovascular diseases (Fig. 17).

Figure 17
Distribution of children in need of palliative care at the end of life by disease groups



The African Region concentrates the majority of children in need of palliative care (49%), followed by the Southeast Asia (24%) and Eastern Mediterranean regions (12%) (Fig. 18). The African Region has the highest rate (160) followed by the Eastern Mediterranean (68) and Southeast Asia (53) regions (Fig. 19).

Figure 18
Distribution of children in need of palliative care at the end of life by WHO regions

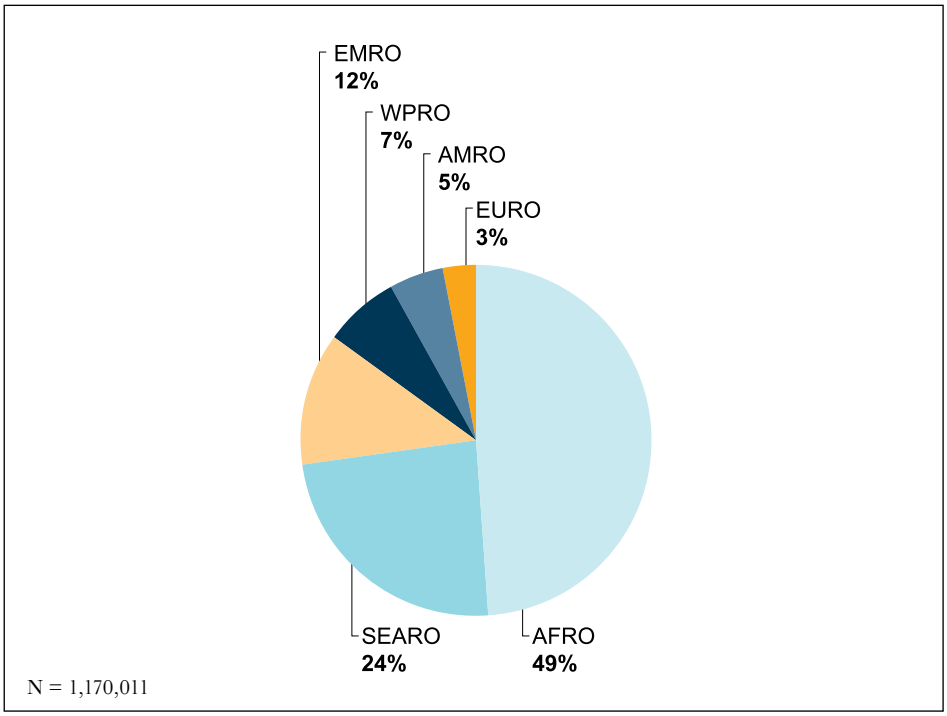
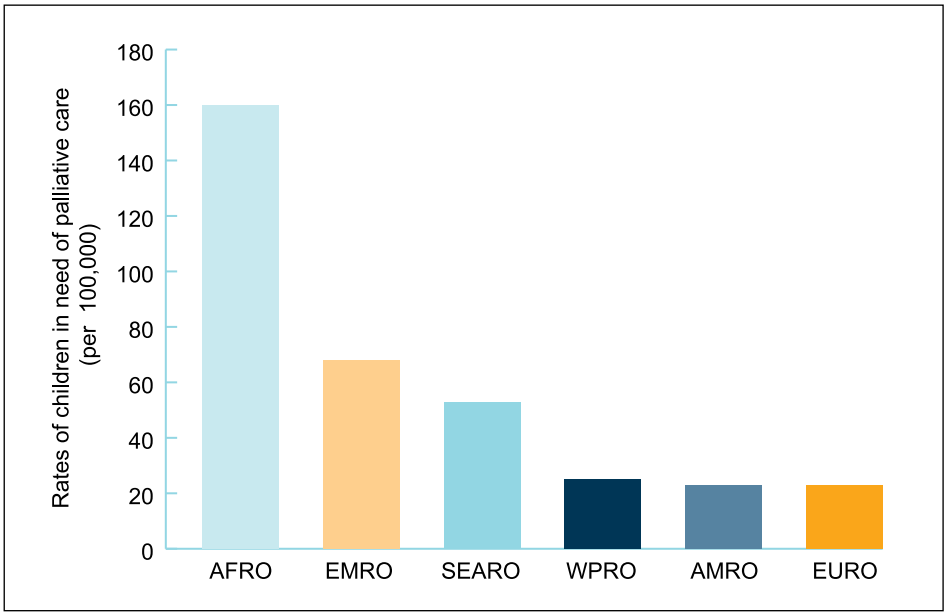
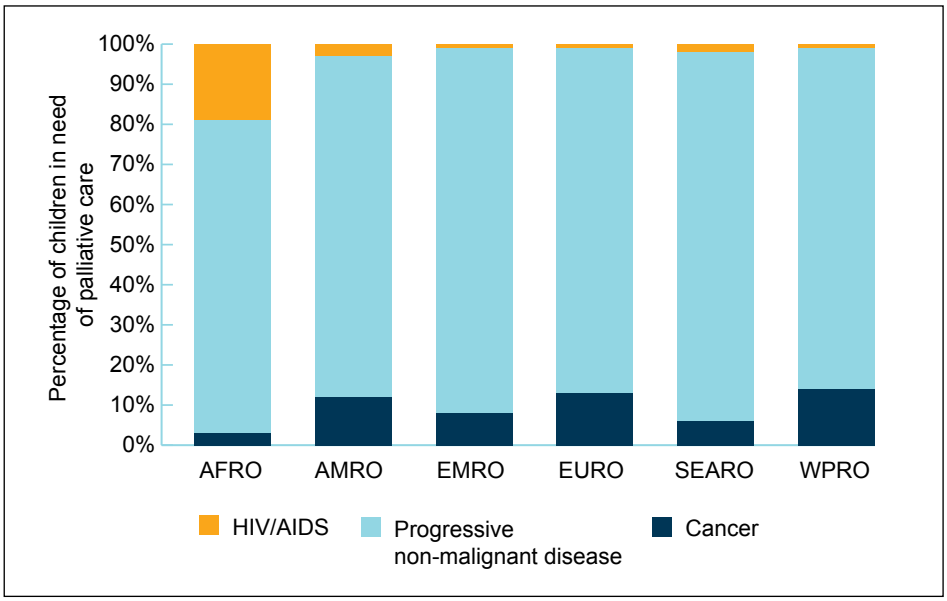


Figure 19
Rates of children in need of palliative care at the end of life by WHO regions



Children in need of progressive palliative care for non-malignant disease constitute by far the highest proportion of cases for all WHO regions (ranging from 78% in the African Region to 91% in the Eastern Mediterranean Region). Palliative care for HIV/AIDS accounts for a small proportion (less than 3%) in every region except for the African Region in which HIV/AIDS represents 19% of children in need of palliative care. The Western Pacific and European regions and Region of the Americas have the highest percentage of children in need of cancer palliative care (14.4%, 12.7% and 11.6% respectively) (Fig. 20).

Figure 20
Distribution of children in need of palliative care at the end of life by WHO regions and disease categories



The vast majority of children (98%) in need of palliative care at the end of life belong to low and middle-income groups. Almost one-half (48.5%) concentrates in the lower middle-income group and over one-third in the low income group (Fig. 21). Moreover, there is indirect correlation between the rates of children in need of palliative care at the end of life with the level of income group. The lower income groups have the highest rates (Fig. 22).

Figure 21
Distribution of children in need of palliative care at the end of life by World Bank country income groups

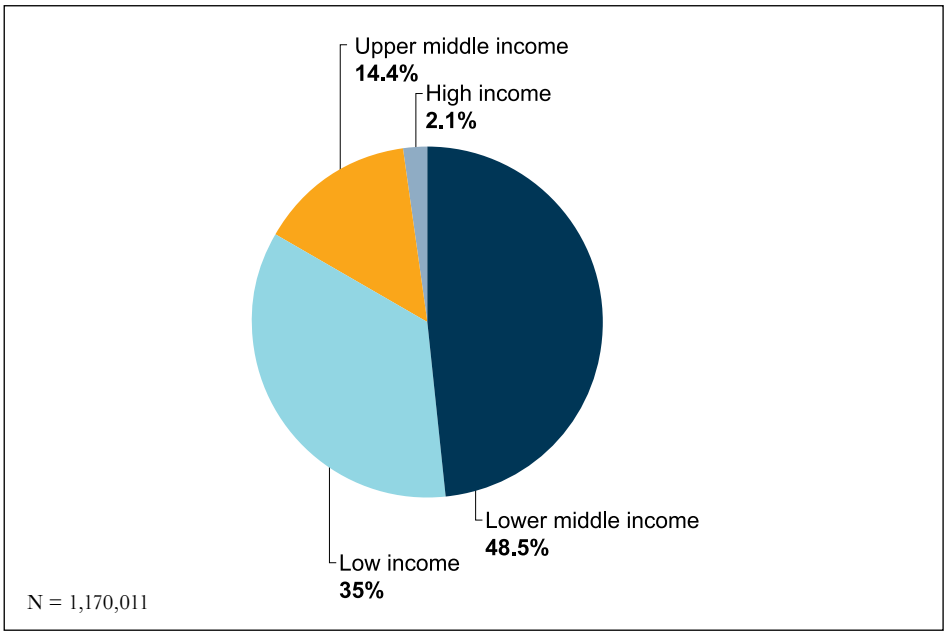
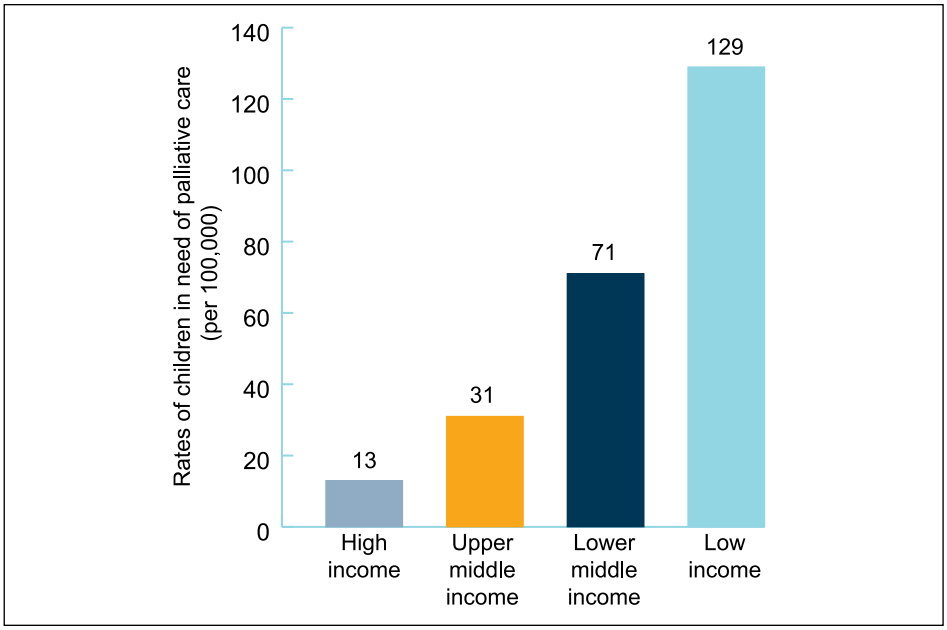
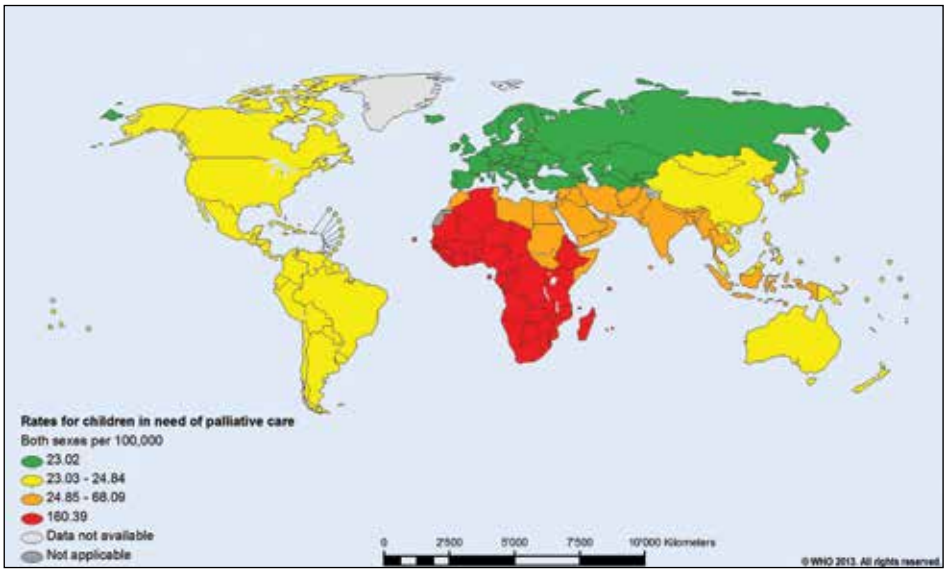


Figure 22
Rates of children in need of palliative care at the end of life by World Bank country income groups



The world map showing the global distribution of rates of children in need of palliative care at the end of life indicates the highest rates in the African, Eastern Mediterranean and South East Asia regions (Fig. 23).

Figure 23
World map showing the global distribution by WHO regions of rates for children in need of palliative care at the end of life



Figures 24 to 26 show the global distribution of rates for children in need of palliative care at the end of life for each disease category: cancer, HIV/AIDS, and progressive non-malignant diseases. The highest rates for children in need of palliative care for cancer are seen in the Eastern Mediterranean, African, Southeast Asia and Western Pacific regions (Fig. 24). In the case of palliative care for HIV/AIDS and non-malignant diseases, the highest rates are seen in the African, Eastern Mediterranean, and Southeast Asia regions (Figs. 25 and 26).

Figure 24
World map showing the global distribution by WHO regions of rates for children in need of palliative care for cancer at the end of life

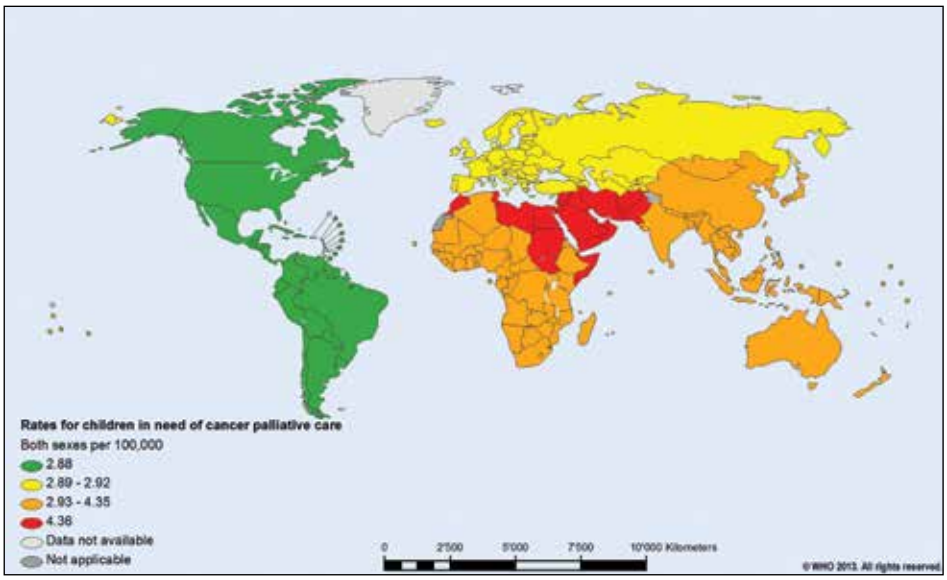


Figure 25
World map showing the global distribution by WHO regions of rates for children in need of palliative care for HIV/AIDS at the end of life

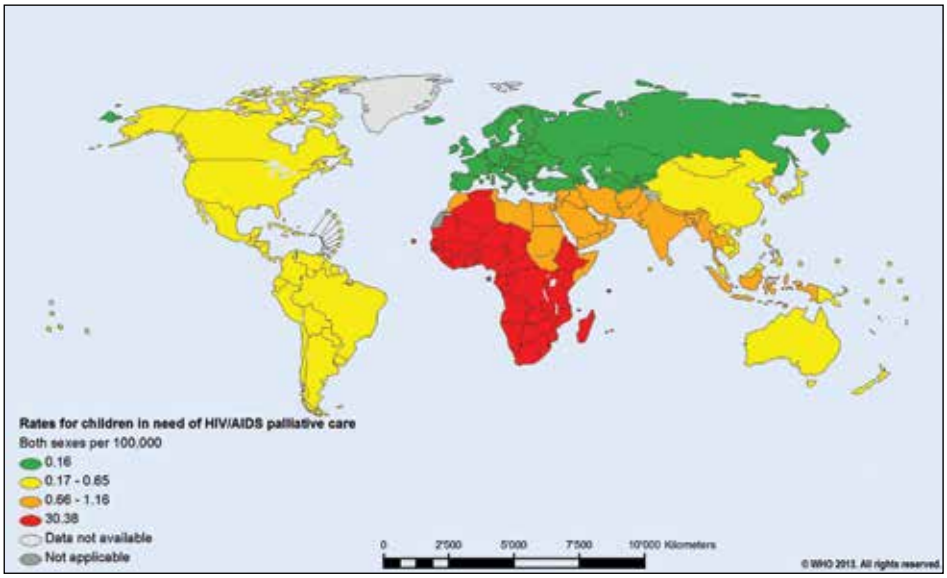
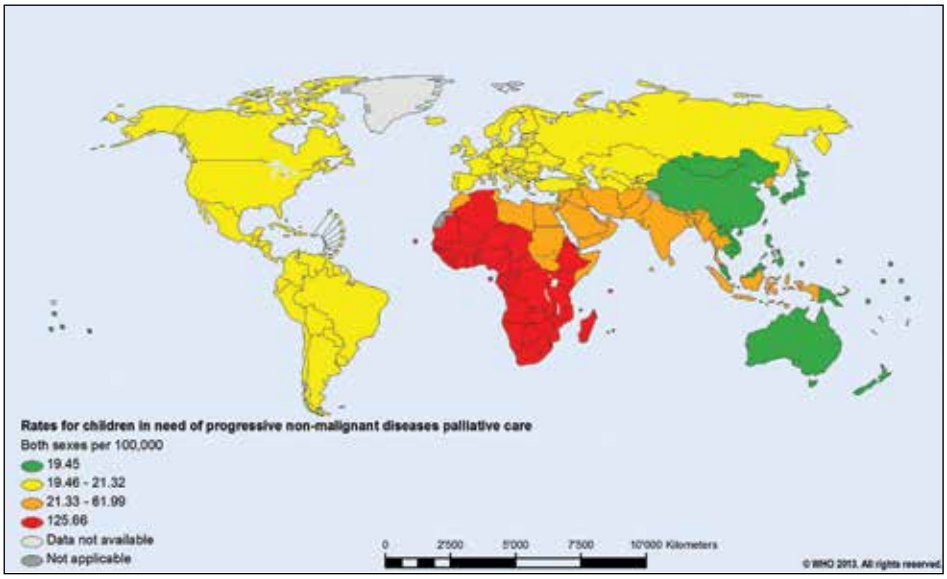


Figure 26
World map showing the global distribution by WHO regions of rates for children in need of palliative care for progressive non-malignant diseases at the end of life



Summary and conclusions

Worldwide, over 20 million people are estimated to require palliative care at the end of life every year. The majority (69%) are adults over 60 years old and only 6% are children.

The highest proportion (78%) of adults in need of palliative care at the end of life live in low and middle-income countries, but the highest rates are found in the higher-income groups. Those dying from noncommunicable diseases represent around 90% of the burden of end of life palliative care. The top diseases are cardiovascular diseases, cancer, and chronic obstructive pulmonary diseases. Together with diabetes and other noncommunicable diseases, they account for the vast majority of adult palliative care needs and tend to predominate in the older age group. The Western Pacific, European and Southeast Asia regions concentrate almost three-fourths of adults in need of end of life palliative care. The highest rates are seen in the European Region, followed by the Western Pacific and Americas regions. Adults in need of palliative care for progressive non-malignant disease represent the highest proportion of cases for all regions, followed by cancer with the exception of the African Region where HIV/AIDS and non-malignant diseases share the same palliative care burden (around 42%) and predominate over malignant diseases.

The vast majority (98%) of children in need of palliative care at the end of life belong to low and middle-income countries, and within this group 83% are in the lower income groups where the highest rates are found. Children dying from congenital anomalies represent over 25% of the burden of end of life care, followed by neonatal conditions (almost 15%) and protein energy malnutrition (14%). The African Region concentrates almost half of children in need of end of life palliative care followed by the Southeast Asia and Eastern Mediterranean Regions. Children in need of palliative care for progressive non-malignant disease represent by far the highest proportion of cases for all regions, whereas palliative care for cancer and HIV/AIDS at the end of life represent a small percentage.

When considered as a percentage of total mortality, this report estimates that 37.4% of all deaths from all causes need palliative care. This is an average number and varies considerably by region and income category. In higher income countries with aged populations the percentage may exceed 60% of total mortality, while in low and middle-income countries the figures are much lower due to higher mortality from infectious diseases and injuries.

This chapter provides estimates of the need for palliative care at the end of life globally and regionally. As said before, the total numbers of patients and caregivers requiring palliative care at some point during life will probably double or triple if we consider the average number of caregivers involved per patient in end of life care and if we include the large numbers of those needing palliative care prior to the end of life.

The above estimates are crucial when advocating for palliative care and are also an important piece of quantitative information for organising resources and services to respond to these pressing humanitarian needs. Nonetheless, it is important to take into account that with intensified health promotion and prevention for avoidable causes of deaths, as well as early detection and timely treatment of potentially curable conditions, a significant number of early deaths from diseases requiring palliative care could be avoided. For example, this is particularly true for children dying from neonatal conditions, protein energy malnutrition, HIV/AIDS and cancer in lower-resource settings, as well as for adults dying from noncommunicable diseases, HIV/AIDS and drug-resistant TB in low and middle-income countries.

Chapter 3

What are the main barriers to palliative care development?

Palliative care development follows a public health model developed by the WHO[33] that emphasises policy, education, medication availability, and implementation. 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 healthcare system;
- national standards of care describing palliative care;
- clinical guidelines and protocols;
- establishment of palliative care as a recognised medical specialty/ sub-specialty;
- regulations that establish palliative care as a recognised type of healthcare provider with accompanying licensing provisions;
- a national strategy on palliative care implementation.

Education

The vast majority of health professionals worldwide have little or no knowledge of the principles and practices of palliative care. All medical professional schools should include basic training on palliative care and continuing professional education should include palliative care for existing health professionals. A growing body of knowledge has been accumulated over the past 40 years on the science of palliative care and palliative medicine. There are now at least 12 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 3 for partial listings).

Palliative care education is needed at three levels:

- basic palliative care training for all health professionals;
- intermediate training for those routinely working with patients with life-threatening illnesses;
- specialist palliative care training to manage patients with more than routine symptom management needs.

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.

Medication availability

Essential palliative care medications, especially opioids, are required for the delivery of quality palliative care. Access to opioid medication for pain control is an enormous problem worldwide. Eighty per cent 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 account for more than 90% of the global consumption of opioid analgesics[34].

The UN 1961 Single Convention on Narcotic Drugs, approved by most countries, called for both limitation on diversion of licit opioids and other psychoactive substances and adequate provision of these drugs for medical and scientific use in a balanced manner. Since that time the major focus has remained on control of illicit use of these drugs with little emphasis on access for medical and scientific use. The worldwide palliative care community and related human rights organisations have advocated for balance to be restored by paying equal attention to both medical use and prevention of illicit use.

While the true need for opioids per capita remains under debate, and will vary by country depending on age, causes of death and many other factors, Seya, et al[35] have published an estimate of opioid need for 188 countries. They used average usage in the 20 top countries in the Human Development Index 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. In 2010 the INCB found more than 100 countries had inadequate consumption of opioids.

Key indicators of availability are the reports of opioid usage by country that are published by the International Narcotics Control Board (INCB)[34]. 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 (see Figures 27 & 28 for country comparisons).

Figure 27
Morphine use worldwide

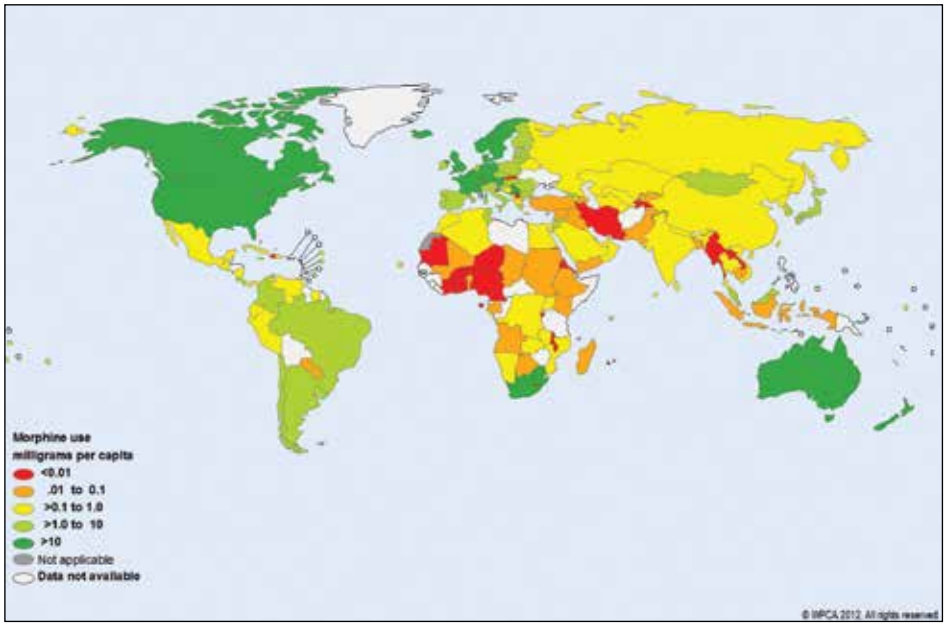
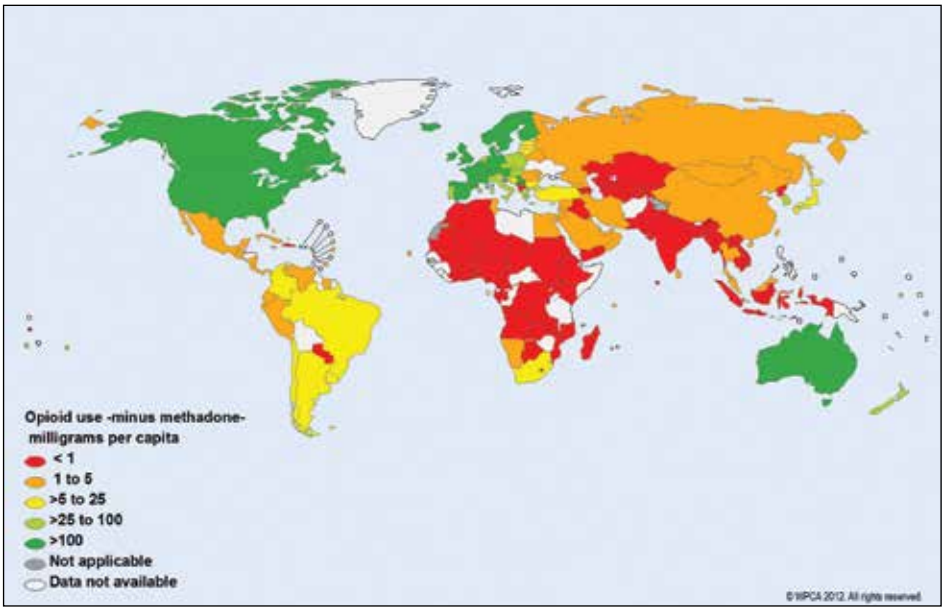


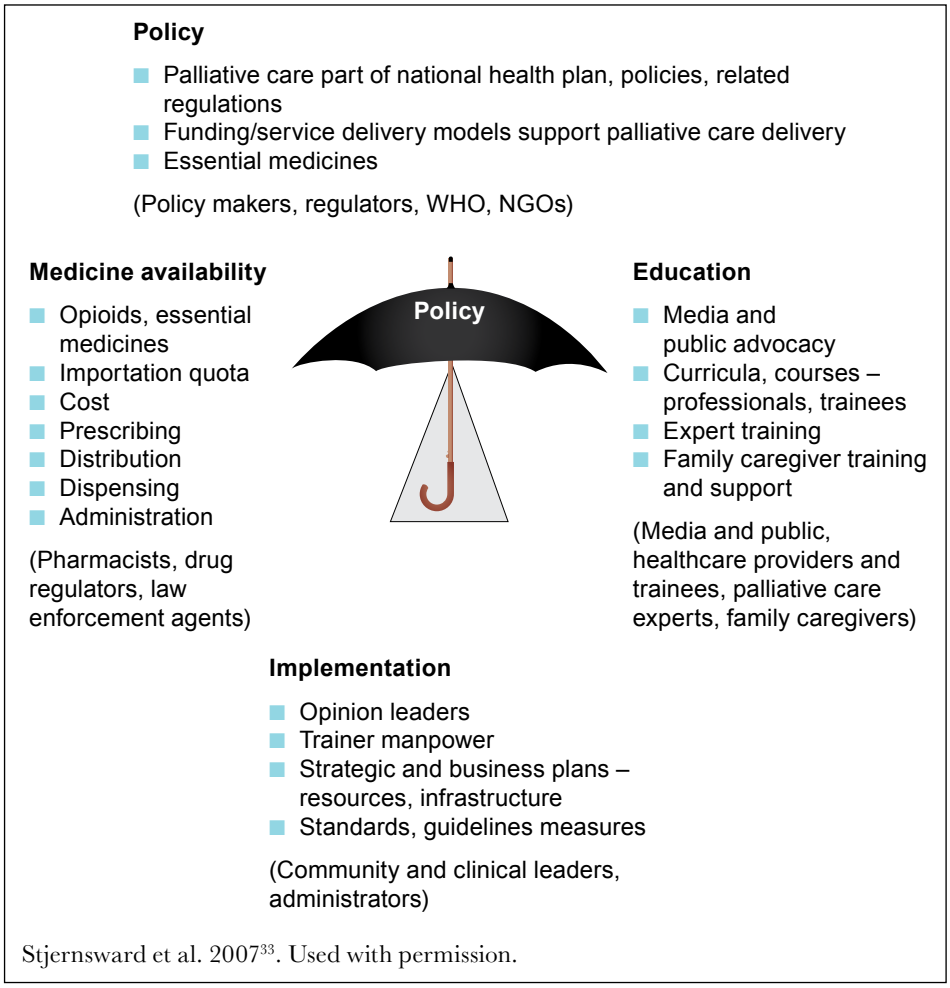
Figure 28
Morphine equivalent total opioid use worldwide



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[36]. 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.

Figure 29
Public health model for palliative care development



Stjernsward et al. 2007[33]. Used with permission.

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. 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 recent evidence points to the possibility that palliative care may actually improve survival[10,37]. However, efforts to engage the public and policy makers on the need for palliative care have met with limited success.

In many countries, informing patients of their diagnosis and prognosis when life threatening is prohibited or strongly discouraged. 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[38,39].

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.

Palliative care for tuberculosis: a new and emerging issue

Palliative care for drug-resistant tuberculosis is a relatively new concept for TB programmes. TB is the second leading cause of death in adults from an infectious disease worldwide after HIV. Mortality is one of the major indicators of the burden of TB and the state of its control in the world. In 2011, 1.4 million deaths were attributable to TB including 430,000 with HIV (equivalent to about 20 deaths per 100,000 population globally). There were an estimated 9.7 million children who were orphans in 2009 as a result of losing at least one of their parents to TB (including HIV-associated TB).

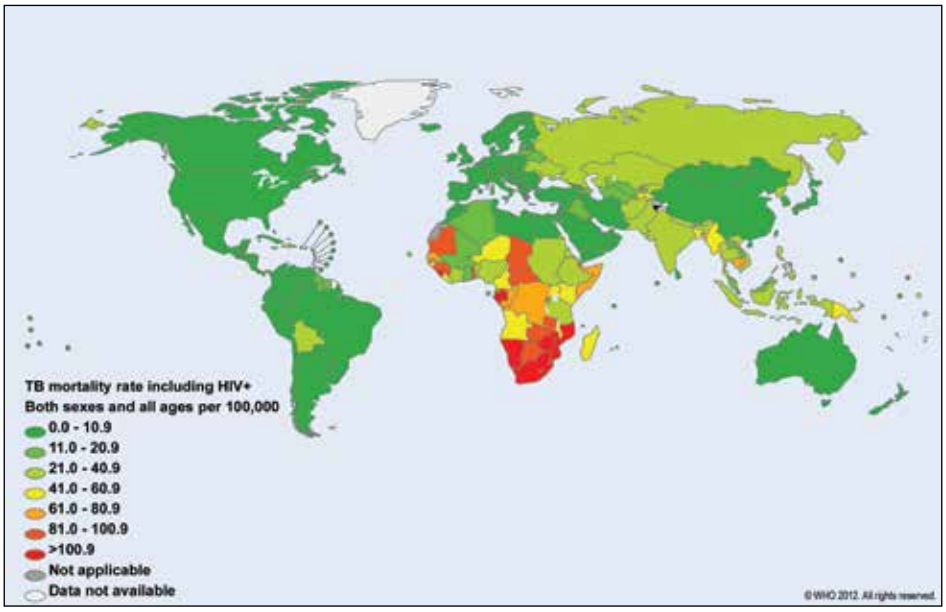
Figure 30 plots the TB mortality in 2010 as a crude rate per population in the country. The statistics include individuals of all ages dying from TB whether they were HIV-positive or not. The data were reported by countries to WHO using information from death certificates collected by national vital registration systems and through mortality surveys, or were estimated in the absence of direct measurement. The map shows the gradient in TB mortality rates using different colours. The highest rates are in southern Africa and are strongly associated with the high

HIV frequency in the population of these countries. However, rates are high also in other areas where HIV prevalence is much lower, such as in southern Asia. The high-income countries are characterised by very low levels of TB mortality.

The WHO Global TB Program has a target to reduce the global TB mortality rate by 2015 to one-half of what it was in 1990. Between 1990 and 2010, TB mortality rates fell by just over a third and the 2015 target is expected to be achieved both at the global level as well as in all regions of the world except the African Region. These positive developments nonetheless mask the harsh reality that most of the 4,000 or so TB deaths which occur each day in the world are preventable.

Without adequate treatment, TB death rates are expected to be high. In studies of the natural history of the disease among sputum smear-positive and HIV-negative cases of pulmonary TB, around 70% died within 10 years. So the early diagnosis of TB and HIV and the rapid institution of treatment are important. 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 multi-drug-resistant tuberculosis (XDR-TB) have been characterised by a 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 late sequelae 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 30
World map showing the global mortality rates for tuberculosis including HIV-positive for all ages (per 100,000, 2010)



Further reading

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Summary and conclusions

Palliative care is still relatively new to national health systems, particularly in low and middle-income countries. 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 essential medications needed to deliver palliative care, and lack of organised 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 recognise 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.

Chapter 4

What is the response to address the needs and barriers to good quality palliative care?

Responding to the enormous unmet need for palliative care has been very challenging. In the 47 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 16,000 hospice or palliative care service units worldwide. 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.

Mapping palliative care development

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 2008 by Wright, Lynch, & Clark[40]. This report measured palliative care development in all countries of the world and classified them according to levels of palliative care development 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).

At the same time it was clear that the rankings might 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. Within the typology changes have been made to the criteria for level of palliative care development in groups 3 and 4 and these have been sub-divided to produce two additional levels of categorisation (groups 3a and 3b/4a and 4b). This new report has been recently published[41] and the main findings are reported in this chapter. (See Appendix 2 for more detail on the methods, limitations, and discussion of results.)

Mapping of paediatric palliative care

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. Figure 38 reports on levels of paediatric palliative care development using the original four-level schema used in 2006, but it also provides

a measure of the progress that still needs to be made and the unique challenges to bringing palliative care to children worldwide.

Number of palliative care providers

In the course of mapping palliative care development by country we have collected data on the approximate number of services providing hospice or palliative care in each country. This data is reported in Figure 39. Having an estimate of the number of services also allowed us to do a preliminary estimate of the number of people receiving palliative care from services that self-identify as providing palliative care (see Figure 40).

Use of opioids for pain relief

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 Pain and Policy Studies Group, a WHO collaborating centre based at the University of Wisconsin (USA). In Chapter 3 we reported on morphine and opioid usage as an indicator of palliative care development (see Figures 29 & 30). This same measure has been approved by WHO as a country level indicator for progress on treatment of non-communicable disease.

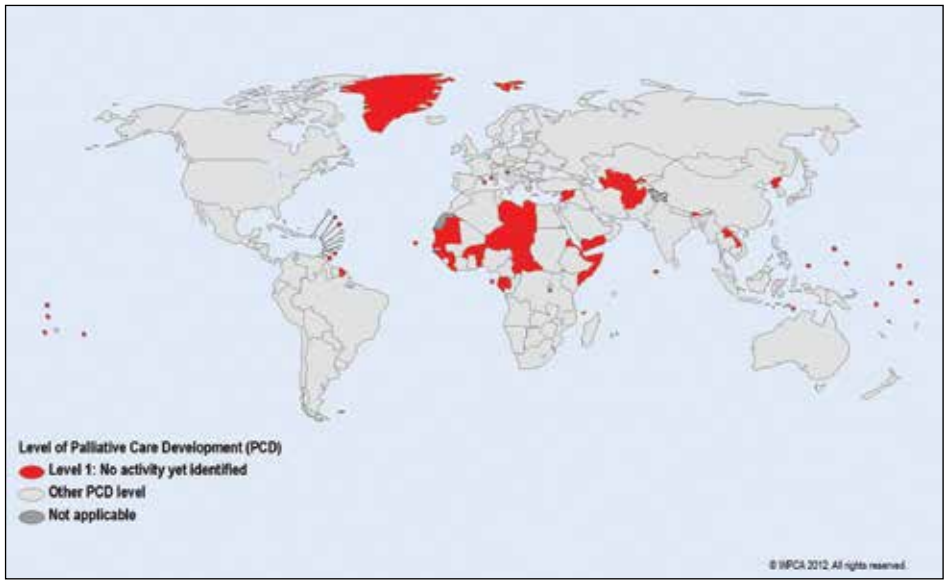
Mapping levels of palliative care development: a global update

WPCA categorisation of palliative care development 2011, N = 234

Group 1 countries:

No known hospice-palliative care activity: Although we have been unable to identify any palliative care activity in this group of countries, we acknowledge there may be instances where, despite our best efforts, current work has been unrecognised.

Figure 31
Countries with no known hospice-palliative care activity (Level 1)



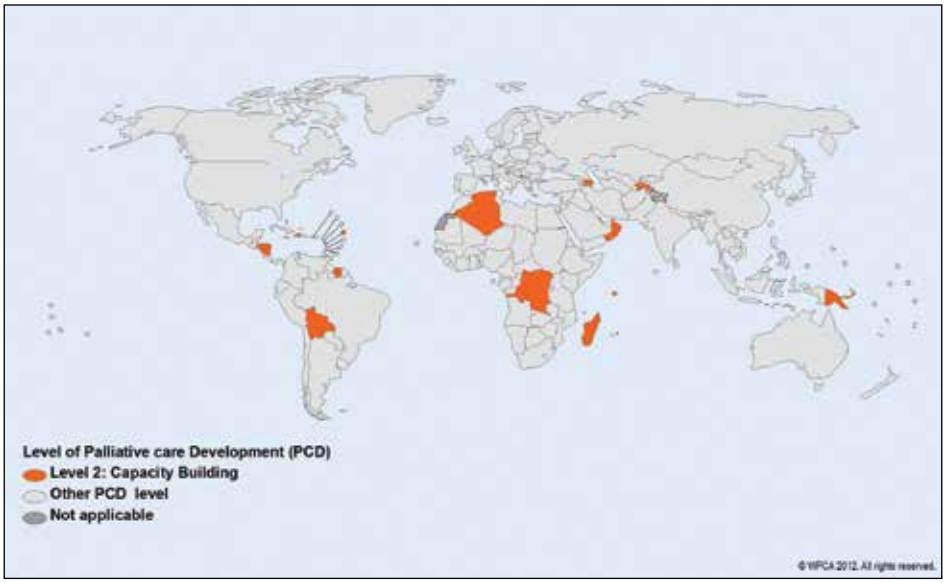
Group 1 No known activity N = 75 (32%)	Afghanistan, American Samoa, Andorra, Anguilla, Antigua and Barbuda, Aruba, Benin, Bhutan, Burkina Faso, Burundi, Cape Verdi, Central African Republic, Chad, Comoros, Cook Islands, Djibouti, Equatorial Guinea, Eritrea, Falkland Islands, Faroe Islands, French Guiana, French Polynesia, Gabon, Greenland, Grenada, Guam, Guinea, Guinea-Bissau, Kiribati, Korea (DPR), Laos, Liberia, Libya, Liechtenstein, Maldives, Marshall Islands, Martinique, Mauritania, Mayotte, Micronesia, Monaco, Montserrat, Nauru, Netherlands Antilles, New Caledonia, Niger, Norfolk Island, Northern Mariana Islands, Palau, Pitcairn, Saint Helena, Saint Kits and Nevis, Saint Pierre and Miquelon, Saint Vincent and the Grenadines, Samoa, San Marino, Sao Tome and Principe, Senegal, Solomon Islands, Somalia, Svalbard, Syria, Timor-Leste, Togo, Tokelau, Tonga, Turkmenistan, Turks and Caicos Islands, Tuvalu, US Virgin Islands, UZBEKISTAN (- from category 2), Vanuatu, Wallis and Fortuna, Western Sahara, Yemen.

Group 2 countries:

Capacity building activity: In this group of countries, there is evidence of wide-ranging initiatives designed to create the organisational, workforce and policy capacity for hospice-palliative care services to develop, though no service has yet been established. The 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 incipient service development.

Group 2 Capacity building N = 23 (10%)	ALAND ISLANDS (- from category 3), Algeria, AZERBAIJAN (- from category 3), Bolivia, British Virgin Islands, Democratic Republic of Congo, Dominica, Fiji, Haiti, Holy See (Vatican), HONDURAS (- from category 3), Madagascar, Mauritius, MONTENEGRO (+ from category 1), Nicaragua, Oman, Palestinian Authority, Papua New Guinea, Qatar, Reunion, Seychelles, Suriname, Tajikistan, The Bahamas.

Figure 32
Countries with capacity building activity (Level 2)



Group 3 countries:

3a) *Isolated palliative care provision.* This group of countries is characterised by: the development of palliative care activism that is patchy in scope and not well supported; sourcing of funding that is often heavily donor-dependent; limited availability of morphine; and a small number of hospice-palliative care services that are often home-based in nature and relatively limited to the size of the population.

3b) *Generalised palliative care provision.* This group of countries is characterised by: the development of palliative care activism in a number of locations with the growth of local support in those areas; multiple sources of funding; the availability of morphine; a number of hospice-palliative care services from a community of providers that are independent of the healthcare system; and the provision of some training and education initiatives by the hospice organisations.

Group 3a Isolated provision N =74 (31.6%)	ANGOLA (+ from category 1), Armenia, BAHRAIN (+ from category 2), Bangladesh, Barbados, BELIZE (+ from category 2), Bermuda, Botswana, Brazil, BRUNEI (+ from category 2), Bulgaria, Cambodia, Cameroon, Cayman Islands, Colombia, Congo, Cuba, Dominican Republic, Ecuador, Egypt, El Salvador, Estonia, ETHIOPIA (+ from category 2), GHANA (+ from category 2), Gibraltar, Greece, Guadeloupe, Guatemala, Guernsey, Guyana, Indonesia, IRAN (+ from category 2), Iraq, Isle of Man, Jamaica, Jersey, Kazakhstan, Korea (South), KUWAIT (+ from category 2), Kyrgyzstan, Latvia, LEBANON (+ from category 2), LESOTHO (+ from category 2), Macedonia, MALI (+ from category 1), Mexico, Moldova, Morocco, MOZAMBIQUE (+ from category 2), Myanmar, NAMIBIA (+ from category 2), Nigeria, NIUE (+ from category 1), Pakistan, Panama, PARAGUAY (+ from category 2), Peru, Philippines, Reunion, Russia, RWANDA (+ from category 2), SAINT LUCIA (+ from category 2), Saudi Arabia, Sierra Leone, Sri Lanka, SUDAN (+ from category 2), The Gambia, Thailand, Trinidad and Tobago, Tunisia, Ukraine, United Arab Emirates, Venezuela, Vietnam.
Group 3b Generalised provision N =17 (7.3%)	Albania, ARGENTINA (- from category 4), Belarus, Bosnia and Herzegovina, COTE D'IVORIE (+ from category 2), Croatia, Cyprus, Czech Republic, Georgia, India, Jordan, Lithuania, Malta, Nepal, Portugal, Swaziland, TURKEY (+ from category 2).

Figure 33
Countries with isolated provision of palliative care (Level 3a)

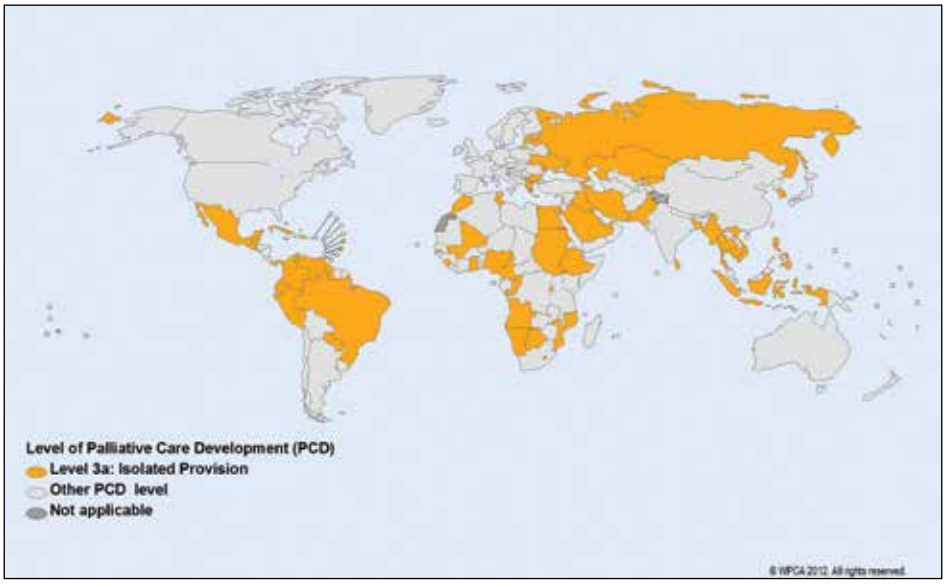
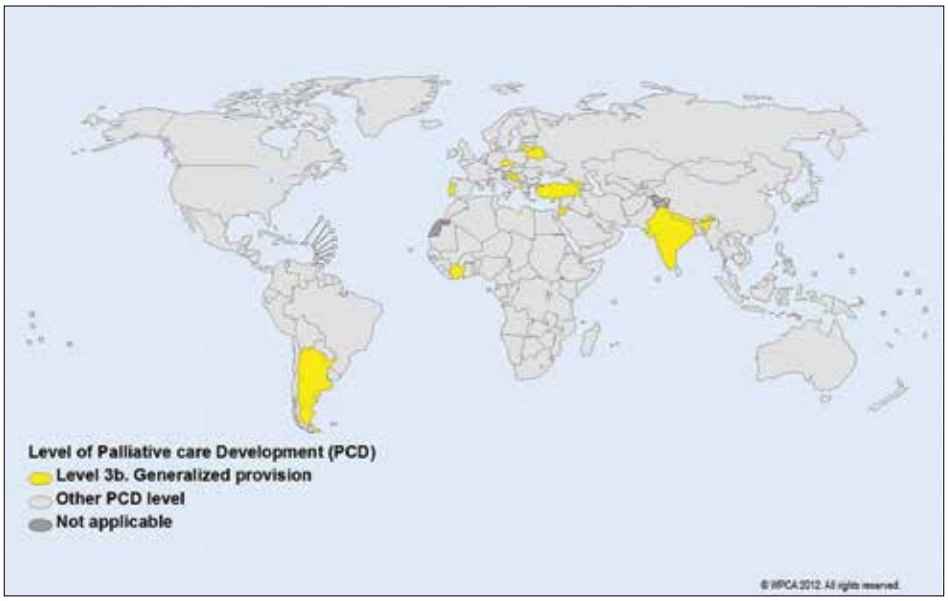


Figure 34
Countries with generalised provision of palliative care (Level 3b)



Group 4 countries:

4a) *Countries where hospice-palliative care services are at a stage of preliminary integration into mainstream service provision.* This group of countries 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; the availability of morphine and some other strong pain-relieving medicines; limited impact of palliative care upon policy; the provision of a substantial number of training and education initiatives by a range of organisations; and interest in the concept of a national palliative care association.

4b) *Countries where hospice-palliative care services are at a stage of advanced integration into mainstream service provision.* This group of countries 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; unrestricted availability of morphine and all other strong pain-relieving medicines; substantial impact of palliative care upon policy, in particular upon public health policy; the development of recognised education centres; academic links forged with universities; and the existence of a national palliative care association.

Global hospice-palliative care development was categorised using the revised typology, country by country, throughout the world; this development is depicted in a series of world and regional maps. The maps presented here make use of the United Nations list of 234 'countries or areas', which are grouped into 21 regions (such as Central America) and then allocated to six 'major areas' designated as 'continents' (Africa, North America, Latin America and the Caribbean, and Oceania). The current number of providers of specialist palliative care services was obtained from the Help the Hospices *Service Database*. The number of hospice-palliative care services was drawn from country reviews, hospice directories, and the opinion of 'key persons' in the field of palliative care; they not only give an indication of activity but, when shown as a ratio of services to population, provide another measure of palliative care development.

Group 4a Preliminary integration N = 25 (10.7%)	Chile, CHINA (+ from category 3), Costa Rica, Denmark, Finland, Hungary, Israel, Kenya, LUXEMBOURG (+ from category 3), MACAU (+ from category 3), MALAWI (+ from category 3), Malaysia, Mongolia, Netherlands, New Zealand, PUERTO RICO (+ from category 2), SERBIA (+ from category 3), SLOVAKIA (+ from category 3), Slovenia, South Africa, Spain, TANZANIA (+ from category 3), URUGUAY (+ from category 3), ZAMBIA (+ from category 3), ZIMBABWE (+ from category 3).
Group 4b Advanced integration N = 20 (8.6%)	Australia, Austria, Belgium, Canada, France, Germany, Hong Kong, Iceland, Ireland, Italy, Japan, Norway, Poland, Romania, Singapore, Sweden, Switzerland, Uganda, United Kingdom, United States of America.

Figure 35
Countries with preliminary health system integration (Level 4a)

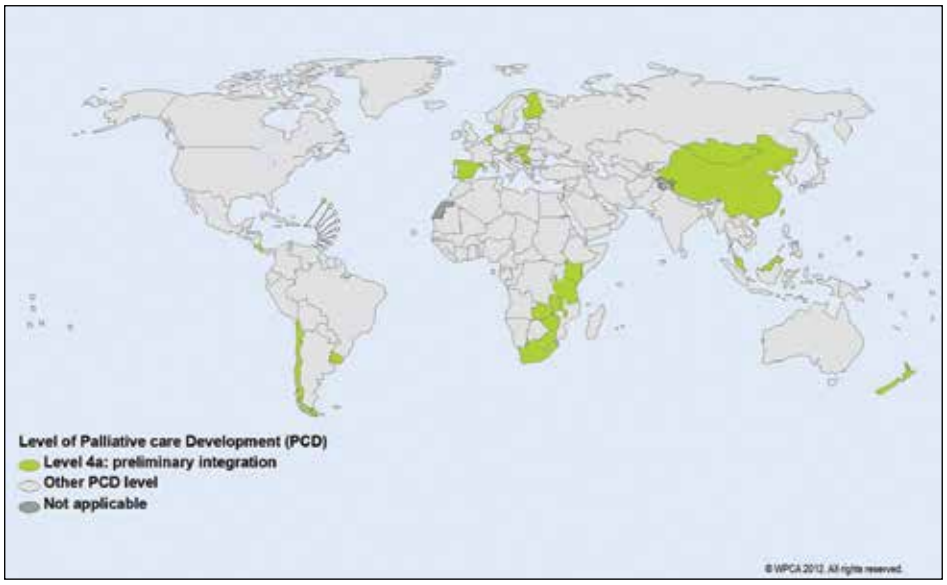
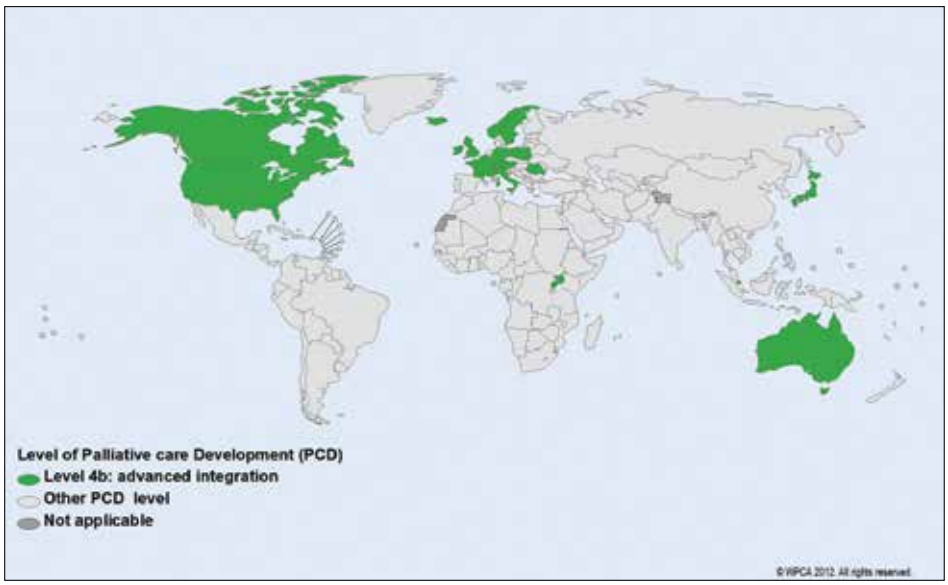


Figure 36
Countries with advanced health system integration (Level 4b)



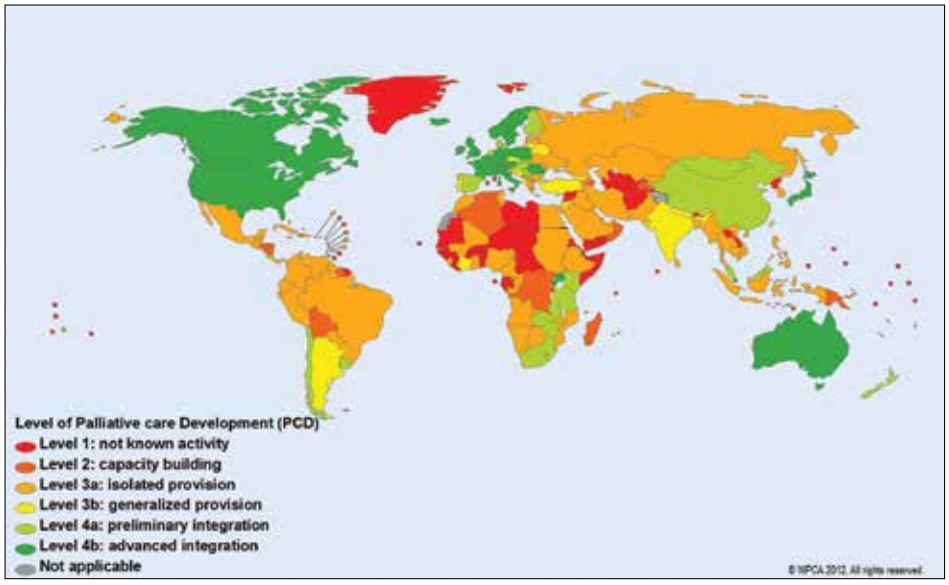
Summary and conclusions

It has been demonstrated that it is possible to map and measure levels of palliative care development, country by country, throughout the world, in order to facilitate cross-national comparative analysis and stimulate advocacy, policy making and service development. In order to provide a more refined view of existing levels of palliative care development, the previous mapping exercise from 2006 was updated; new data were collected and the typology amended. Limitations to the project included: an absence of data for some countries; problems in the counting and categorisation of services; self-reporting by 'key persons' may have been subject to bias or inaccuracy; and respondents experienced difficulty in choosing between the newly divided categories.

In 2011, 136 of the world's 234 countries (58%) had one or more hospice-palliative care services established – an increase of 21 countries (+9%) from the previous project (2006). A regional analysis of palliative care development between 2006 and 2011 indicates that the most significant gains have been made in Africa, although the impact that the withdrawal of support by The Diana, Princess of Wales Memorial Fund from the region in 2012 will have on the continued development of palliative care is as yet unknown. A significant number of countries still have no hospice-palliative care provision and global development may best be described as 'patchy'. Although there are indications of palliative care interest on the part of national governments and policy makers, advanced integration of palliative care with wider health services has been achieved in only 20 countries globally (8%). Despite increasing calls for palliative care to be recognised as a human right, there remains much to be done before palliative care is accessible to the worldwide community.

This project has built on the original work of the International Observatory on End of life Care (IOELC), which was pioneered by Professor David Clark and Dr. Michael Wright. It is hoped that the results of this project will serve to stimulate further discussion about the use of the typology for raising awareness of the need for integrating palliative care into existing healthcare systems. The increased interest in access to palliative care as a human right provides further justification for examining the relationship between palliative care services and their accessibility to the populations of individual countries.

Figure 37
Levels of palliative care development – all countries



Paediatric palliative care development

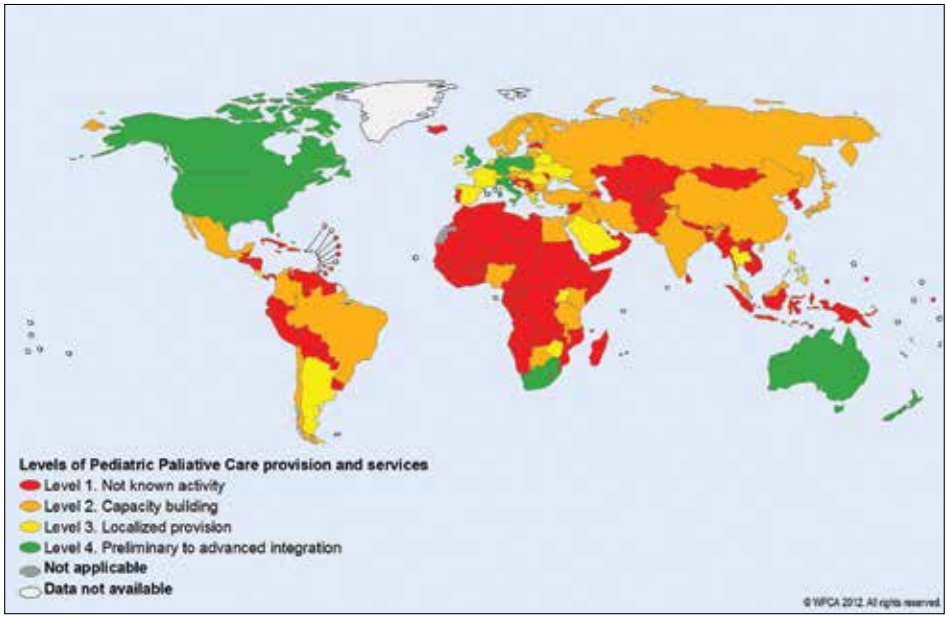
A separate study on paediatric palliative care development was recently done that parallels the mapping of adult palliative care[42]. The provision of care to children with life-limiting illnesses differs in some important ways from adult palliative care. Children are more resilient and are not 'little adults'. Prognostication is more uncertain and treatment approaches are often more aggressive. Like adult palliative care the provision of palliative care to children is currently limited to high-resource countries as shown in figure 12.

Around the world children are suffering from illnesses that range from HIV to cancer. It has been estimated that each year seven million children could benefit from paediatric palliative care. Governments, private businesses, charitable foundations, non-governmental organisations, hospices, and palliative care programmes provide resources to some of these children and their families. The modern day hospice-palliative care movement was born in England in the 1960s when the first hospice, St. Christopher's, opened in London. Since that time, paediatric palliative care has been recognised as a distinct specialty. Guidelines, definitions, and the scope of paediatric palliative care have been published over the last two decades by several national and international organisations. Other factors have also advanced the modern hospice-palliative care movement for children. Advocates, professional conferences, training modules for nurses and physicians, and the Internet are just a few mechanisms that have helped to increase the provision of paediatric palliative care.

There is no central repository to track this progress, yet there is a need to understand where countries are in the evolution of service provision. Provision is an ever-changing concept. Grassroots efforts are often credited with spreading the word, training workers, and explaining the importance to stakeholders. Following the initiation of such efforts, provision usually begins on a local level and then with time, monetary, and other resources, local provision is sustained. Once local programmes have become established, additional programmes may emerge in the same location or spread to other areas. Ultimately, paediatric palliative care should be accessible to all children regardless of where they live. However, information on the level of provision does not currently exist. This information will help decision makers to determine where additional resources are needed, to advance countries from high levels of capacity building activities to actual provision, or to identify where basic resources are needed to begin capacity building activities.

Recent research from UNICEF and the International Children's Palliative Care Network has begun to establish a methodology for determining the need for children's palliative care. This methodology has been tested in three African countries (available at: www.icpcn.org/wp-content/uploads/2013/11/Assessment-of-the-Need-for-Palliative-Care-for-Children.-Three-Country-Report-South-Africa-Kenya-and-Zimbabawe.pdf)

Figure 38
Levels of paediatric palliative care development – all countries



Supplemental Table II. Countries by Level

	#	%	Countries
Level 1	126	65.63%	Afghanistan, Algeria, Andorra, Angola, Antigua and Barbuda, Azerbaijan, Bahamas, Bahrain, Barbados, Belize, Benin, Bhutan, Bolivia, Brunei Darussalam, Burkina Faso, Burundi, Cambodia, Cameroon, Cape Verde, Central African Republic, Chad, Comoros, Congo, Cote D'Ivoire, Croatia, Cuba, Democratic People's Republic of Korea, Democratic Republic of the Congo, Djibouti, Dominica, Dominican Republic, Ecuador, El Salvador, Equatorial Guinea, Guatemala, Guinea, Guinea Bissau, Guyana, Honduras, Iceland, Indonesia, Jamaica, Kazakhstan, Kiribati, Kuwait, Kyrgyzstan, Lao People's Democratic Republic, Lebanon, Lesotho, Liberia, Libyan Arab Jamahiriya, Liechtenstein, Luxembourg, Madagascar, Maldives, Mali, Malta, Marshall Islands, Mauritania, Mauritius, Federated States of Micronesia, Monaco, Mongolia, Montenegro, Morocco, Mozambique, Myanmar, Namibia, Nauru, Nepal, Nicaragua, Niger, Oman, Pakistan, Palau, Panama, Papua New Guinea, Paraguay, Peru, Portugal, Qatar, Republic of Korea, Republic of Moldova, Rwanda, Saint Kitts and Nevis, Saint Lucia, Saint Vincent and the Grenadines, Samoa, San Marino, Sao Tome and Principe, Senegal, Serbia, Seychelles, Sierra Leone, Solomon Islands, Somalia, Sri Lanka, Sudan, Suriname, Syrian Arab Republic Tajikistan, The Former Yugoslav Republic of Macedonia, Timor-Leste, Togo, Tonga, Trinidad and Tobago, Tunisia, Turkmenistan, Tuvalu, United Arab Emirates, Uruguay, Uzbekistan, Vanuatu, Bolivarian Republic of Venezuela, Viet Nam, Yemen, and Zambia
Level 1	126	65.63%	Albania, Armenia, Austria, Bosnia and Herzegovina, Botswana, Brazil, Bulgaria, Chile, China, Columbia, Cyprus, Denmark, Egypt, Finland, Georgia, Haiti, India, Islamic Republic of Iran, Iraq, Japan, Jordan, Kenya, Lithuania, Malawi, Malaysia, Mexico, Nigeria, Norway, Russian Federation, Singapore, Slovakia, Slovenia, Swaziland, Sweden, Turkey, and United Republic of Tanzania
Level 3	19	9.90%	Argentina, Belarus, Costa Rica, Czech Republic, France, Greece, Hungary, Ireland, Latvia, Netherlands, Philippines, Romania, Saudi Arabia, Spain, Switzerland, Thailand, Uganda, Ukraine, and Zimbabwe.
Level 4	11	5.73%	Australia, Belgium, Canada, Germany, Israel, Italy, New Zealand, Poland, South Africa, United Kingdom, and United States of America

Palliative care services in relation to population

We asked palliative care leaders in as many countries as we could to tell us how many identified palliative care services existed nationally and also used our international directories to count the number of providers. The result was that approximately 16,000 service units were identified worldwide. Another way of looking at the availability of palliative care is to examine the relationship between the number of providers and service delivery units to the population in a country. The range of providers to population varies enormously. Globally it ranges from 1: 1000 (in Niue, an island country in the South Pacific Ocean) to 1: 90 million (in Pakistan) (see Figure 39).

Ratio of palliative care services to population

	Lowest	Services; n=	Ratio 1:000s	Highest	Services; n=	Ratio 1:000s
Group 3a	Niue	1	1	Pakistan	2	90 404
Group 3b	Lithuania	65	51	Turkey	14	5344
Group 4a	Netherlands	295	56	China	159	8511
Group 4b	Austria	247	34	Uganda	34	962

Numbers of patients receiving palliative care

The number of patients receiving specialised palliative care worldwide is unknown. The only reliable registry of palliative care patients receiving hospice care is in the United States where numbers of patients enrolled in the Medicare Hospice Benefit are tracked. In addition the National Hospice and Palliative Care Organization collects data on the number of hospice patients not receiving Medicare benefits[43]. Using NHPCO data and the number of known palliative care teams by country, we estimate the numbers of patients that die while receiving palliative care services is in the region of three million patients, or about 14% of those needing palliative care at the end of life worldwide (Figure 40).

Figure 39
Services/providers to base population (per 1M population)

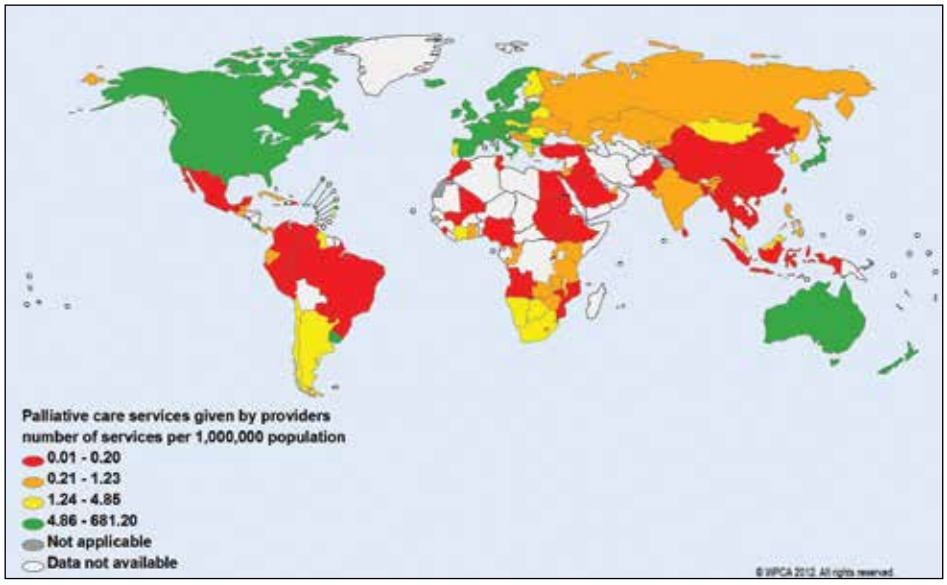
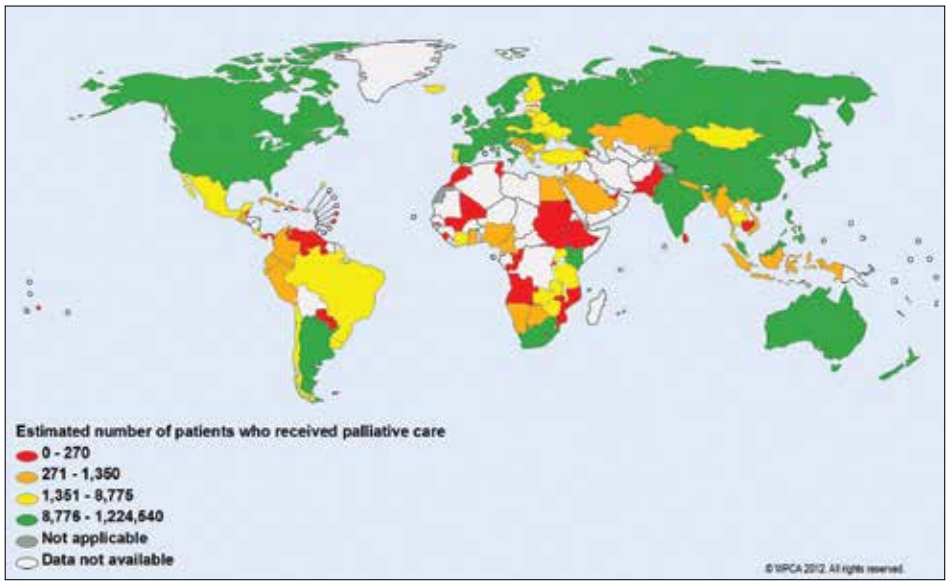


Figure 40
Estimated number of patients receiving palliative care



Chapter 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 two examples of programmes (Kerala, India and Arusha, Tanzania) that make effective use of volunteer community health workers; a beacon for palliative care training and advocacy (Brasov, Romania); a programme that has achieved the highest level of penetration in the population needing palliative care (Florida, US); a programme that has introduced palliative care into the government-run health system (Vietnam); a programme that has introduced palliative care into acute facilities (Argentina); and a quality hospice programme in the United Kingdom. There are many more excellent programmes that could have been included here were space available. 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.

India

Neighbourhood Network in Palliative Care, Kerala, India

Description of the model

Neighbourhood Network in Palliative Care (NNPC), a community-owned programme in Kerala (India), is a project evolved out of a series of needs-based experiments in the community. In this programme, initiated in the year 2000, volunteers from the local community are trained to identify problems of the chronically ill in their area and to intervene effectively, with active support from a network of trained professionals. Essentially, NNPC aims to empower local communities to look after the chronically ill and dying patients in the community. It is inspired by the concept of primary healthcare described by the World Health Organization in the Declaration of Alma-Ata: "Primary healthcare is essential healthcare based on appropriate and acceptable methods and technology made universally accessible to individuals and families in the community through their full participation and at a cost the country and the community can afford, to maintain the spirit of self-reliance." Within 10 years, the initiative has grown into a vast network of more than 500 community-owned palliative care programmes looking after more than 15,000 patients at any one time. It has a workforce of over 15,000 trained community volunteers, 50 palliative care physicians, and 100 palliative care nurses.

Home care patient

Level of support from the existing health system

The challenge before palliative care workers in the developing world is to evolve a culturally and socio-economically appropriate and acceptable system for long-term care and palliative care, accessible to most of those who need it. This can be possible only if the service is part of a community-based primary healthcare system using local manpower and other resources. Many authors have highlighted the role of community participation in placing palliative care within this holistic context.

Innovations to highlight

All the palliative care units in the network have outpatient services led by palliative care physicians. The doctor-nurse teams that manage these outpatient clinics are employed by the local community volunteer groups. The number of outpatient clinic days per week varies from unit to unit. Patients registered at one unit can also attend an outpatient clinic run by another unit. Community volunteers visit most patients at home. In addition, all the units offer regular nurse-led home care services, supplemented by home visits by doctors. Services offered by outpatient clinics and professional home care units include medical consultations, medicines, procedures like tapping of ascetic fluids, and wound care. Neighbourhood network groups also offer emotional support to patients, food for the needy patients and family, educational support to their children, transport to hospital when required, and social rehabilitation programmes in addition to the medical and nursing services.

Sustainability

The NNPC is a highly sustainable model due to direct ownership by the community. In addition, the local and state governments, which values NNPC's services to the communities, provided $3.6 million in parallel support.

Group meeting

Tanzania

Continuum of Care for Persons Living with HIV/AIDS in Tanzania (CHAT)

Description of the model

Continuum of Care for People Living with HIV/AIDS in Tanzania (CHAT) is a project which started in 2006 with the aim of adding palliative care capacity to home-based care programmes throughout the Lutheran healthcare system in Tanzania. The overall goal was to significantly enhance the continuum of care for Tanzanian people living with HIV/AIDS and their families, including orphans and vulnerable children (OVC), by scaling up palliative care capacity and linking with existing Lutheran hospitals and church congregations throughout Tanzania.

CHAT was a USAID-funded project and the Foundation for Hospices in Sub-Saharan Africa (FHSSA) was the lead agency that provided project oversight, technical assistance, coordination and administration. The implementing agency in Tanzania is the Evangelical Lutheran Church of Tanzania (ELCT), with its headquarters in Arusha. ELCT already operated a model palliative care programme at Selian Lutheran Hospital and Hospice and this was extended to 13 other hospital sites and their surrounding communities.

Level of support from the existing health system

Over the last century, ELCT has grown to be one of the major health service providers in Tanzania, with nearly 15% of the national population receiving health services from ELCT facilities. About 14,000 palliative care clients and 13,500 most vulnerable children were supported during the project life. Some of these activities will be taken over by the existing HIV support programmes both from NGOs and the government.

Innovations to highlight

Day care where palliative care clients not only received care near their homes, but also their spouses and children received free voluntary counseling and testing services at the same time. In a country where the use of morphine for management of palliative care and severe pain has been extremely low, our programme, in collaboration with other major stakeholders, made morphine available at 12 out of our 13 project sites.

Sustainability

Many of the full-time staff for the project were also permanent employees of the hospital, and hence they will continue doing palliative care work. All 13 project sites were linked with a US-based hospice partner by FHSSA's twinning programme. As part of sustainability, these US partners will continue supporting their respective ELCT partners to further improve their palliative care activities. Prior to the conclusion of USAID funding, the ELCT palliative care programme was able to secure some other donors to further their palliative care agenda. These included the Evangelical Lutheran Church in America, and AFRICARE. The Lutheran church network will continue supporting the psychosocial aspects of the OVC and palliative care clients' needs by using locally raised funds, gifts in kind and various other locally available support mechanisms.

Romania

Hospice Casa Sperantei – Brazov, Romania

Description of the model

Hospice Casa Sperantei is a Romanian charity founded in 1992 in Brasov, in partnership with a British hospice based in Dartford, Kent. Its mission is to introduce and support the development of hospice and palliative care for patients with incurable diseases in advanced and terminal stages in Romania. Services started in 1992 in the city of Brasov as home-based palliative care for adults and extended in 1996 with paediatric palliative care in the children's homes. In 2002 the first Romanian purpose-built teaching hospice was opened in Brasov, hosting a 13-bedded adults inpatient unit and a six-bedded unit for children, as well as day centres and outpatient clinics for adults and children with cancer and other life-limiting conditions.

The organisation has been actively involved since 1997 in the education of professionals interested in setting up new palliative care services (over 12,000 doctors, nurses, social workers, psychologists, therapists, clerics and carers), as well as over 500 volunteers. Hospice Casa Sperantei is actively involved in introducing palliative care in the undergraduate training of medical and nursing students (University of Brasov) and since 2010 a two-year masters degree in palliative care is available at the same university.

Hospice Casa Sperantei has made a major contribution towards raising awareness about the need for palliative care in Romania, in improving the legal framework to allow better access of patients to pain control medication, in the recognition of palliative care as a medical competence, and developing minimum standards for palliative care services. It has also contributed to setting up some of the funding mechanisms for hospices and palliative care services.

Level of support from the existing health system

In 2010, the healthcare system reimbursed part of the medical costs for admissions in the inpatient units and of the outpatient consultations. Home-based palliative care services provided to over 1,400 patients in 2010 were not covered, due to the scarce financial allocations. The social component of the palliative care services (day centres) are subsidised by funding from the Ministry of Labour and Social Protection and the local authority.

Innovations to highlight

Hospice Casa Sperantei is a resource centre for palliative care development in eastern Europe, providing theoretical and clinical palliative care courses for countries in the Balkan region and Commonwealth of Independent States (CIS) countries. It provides a complex of free-of-charge palliative care services in the Brasov county (Brasov, Fagaras and Zarnesti areas) and in Bucharest, in various settings, for adult patients with cancer and children with various life-threatening diseases covering over 1,700 patients every year. The model developed over the past 19 years in Brasov provides an integrated approach, where patients admitted in the programme can choose and receive care either at home, or in the hospice (inpatient admissions, outpatient consultations, day centre attendances), adapted to the stage of the disease. The model has been replicated by several other hospices and palliative care services throughout Romania.

Sustainability

Our clinical services are partly supported by the health insurance system (21%). The steady development of the services and education programmes were possible due to the constant support of the charity Hospices of Hope (United Kingdom), through international grants from USAID, the EU, PHARE (Poland and Hungary: Assistance with restructuring their economies programme), SOROS, Open Society Institute New York, international organisations (NHPCO, Blue Heron Foundation, British National Lottery), national and multi-national companies (GlaxoSmithKline, Vodafone, Lloyds TSB, Vitol, Merck Sharp&Dohme, Bristol Myers Squibb) and other charitable organisations, as well as from our own local fundraising efforts, the Brasov authorities and community.

In 2010, the hospice programme was financially sustained from the following sources: 20% reimbursements from the health system (inpatient and outpatient services), 15% from the foreign partner organisation, 25% individual donations, 17% international grants, 15% charitable events, and 8% corporate contributions.

Florida USA

Hope Hospice – Ft. Myers, Florida USA

Community-based palliative care: sharing Hope with the community

Description of the model

The demand for palliative care skills and services is not limited to those with a clear end of life prognosis and eligibility for the US Medicare hospice benefit. At Hope Hospice, we realised there was an increasing need for our special kind of care by those who were not eligible for hospice benefit. We were one of many that pioneered the concept of access for all and set a goal to expand the scope of our care to reach more people in need. We did this through the utilisation of our core skills including pain control, symptom management, bereavement counselling and person-centred care that includes the family. This care is appropriate in all settings and is provided through an interdisciplinary team approach. With this focus, Hope has implemented an array of coordinated care programmes, each with its own staff, that focus on quality of life through palliative care.

Hope provides hospice and palliative care to newborns and children who have a life-limiting illness, focusing on aggressive symptom management and pain control to ensure quality of life. The US state of Florida has a very large elderly population. Our programmes for the elderly enable adults to remain in the place they call home, providing daily living assistance, proactive medical care and innovative disease management. This coordinated approach to palliative care eliminates the fragmented services that caregivers must often seek in the US healthcare system.

Level of support from the existing health system

In expanding our circle of care, Hope has collaborated with all area hospitals, nursing homes, assisted living facilities, specialists and other agencies. This has resulted in additional cost-saving efficiencies, increased levels of service, and a more robust referral network.

Innovations to highlight

Our innovations can serve as a model that will enable more people with chronic illnesses to gracefully transition from futile and expensive treatments to quality palliative care and services. Through collaboration and the open access facilitated by our enhanced circle of care, Hope cares for 73% of all people at the end of life in our service area; the national average is 41.6%. Hope has shown that there is a high level of need for palliative care in a community and that that need can be met by palliative care services. Through each of these new programmes, we are significantly increasing the number of people we serve on a daily basis. Currently Hope serves approximately 2,800 people each day, and their families.

Sustainability

As we introduced these new programmes of care, we accessed new revenue streams and found new economic efficiencies. Revenue sources include Medicare, Medicaid, insurance, private pay, grants and community support. Only limited expansion was required for our administrative services and infrastructure. Existing IT tools and systems now have lower operating costs as a benefit of the economy of scale.

Vietnam

Model Palliative Care Programme in Vietnam: Ho Chi Minh City Cancer Hospital

Description of the model

The Ho Chi Minh City Cancer Hospital is southern Vietnam's largest and busiest cancer centre with approximately 1,700 inpatients on any given day and approximately 9,000 active outpatients. Its leaders recognised the medical and moral imperative of adding palliation to its mission to prevent, diagnose early, and treat cancer. The leaders aimed to ultimately offer the full range of palliative care services but focused initially on training. The hospital invited the Harvard Medical School Center for Palliative Care (HMSCPC) to begin basic and advanced training in palliative care for interested medical staff members (curricula available online at: www.massgeneral.org/palliativecare/education/international_program.aspx) and opened a four-bed palliative care ward staffed by its newly trained physicians. Each physician who successfully completed training in palliative care was given authorisation to prescribe opioid analgesics. In January 2011, the hospital opened a department of palliative care that includes a 10-bed inpatient ward, an outpatient clinic, and palliative care consultation on demand. In summer 2011, it added a model home care team designed to be sustainable and replicable by other departments and hospitals.

Level of support from the existing health system

In 2005, the Ministry of Health (MoH) launched a palliative care initiative with financial assistance from the US President's Emergency Plan for AIDS Relief (PEPFAR) and the Open Society Foundations, and with technical assistance primarily from the HMSCPC. The MoH carried out a rapid situation analysis of palliative care needs in 2005, issued national guidelines on palliative care in 2006, and issued revised opioid prescribing regulations reflecting international standards in 2008. To date, the MoH has not provided hospitals with funding specifically for palliative care. However, hospitals have some discretion to use their government funding for palliative care if they wish.

Innovations to highlight

Revision of national opioid policy: The senior pharmacy specialist from the Vietnam Ministry of Health participated in the International Pain Policy Fellowship of the Pain & Policy Study Group at the University of Wisconsin Cancer Center (US). This innovative programme provides palliative care clinicians and MoH officials from developing countries with mentoring and two years of funding to review their country's laws and regulations governing opioid accessibility and to revise them as needed to make opioids readily available for medical purposes. Vietnam's radical revision in 2008 of its opioid prescribing regulations brought them in line with international standards for the first time and made it possible for cancer and HIV/AIDS patients to receive adequate pain relief both in the hospital and at home.

Sustainability

The commitment of the Ho Chi Minh City Cancer Hospital to developing sustainable palliative care services is indicated by its use of discretionary funds for this purpose. Inpatient and outpatient palliative care services are billed to the patients' insurance providers. The great majority of Vietnamese cancer patients die at home, and palliative home care is therefore essential. Yet health insurance does not currently cover home care despite the cost savings that might be realised by helping families care for dying patients at home rather than admitting them to the hospital. Until such insurance coverage is secured, one strategy to make palliative home care sustainable entails charging wealthy patients more than the usual cost for home care and using the extra revenue to pay for free home care for the poor.

Argentina

Programa Argentino de Medicina Paliativa – Fundación FEMEBA

Description of the model

The Programa Argentino de Medicina Paliativa-Fundación FEMEBA (PAMP-FF, http://paliativo-femeba.org) is a not-for-profit non-governmental organisation to promote palliative care nationwide. It began in 1983 in LALCEC (Liga Argentina de Lucha contra el Cáncer) San Nicolás, Buenos Aires, Argentina, and since 1994 the FEMEBA Foundation has driven its continuous development.

Its progress followed phases of growing complexity and activity.

1) The Palliative Care Unit, Hospital Tornú, Buenos Aires city. The unit is in a building with waiting room, two offices, five bedrooms for up to six inpatient beds, and an area for families and team meetings.

2) PACI (Programa de Asistencia Integral Continua – or Continuous Comprehensive Caring Programme), a regional programme with a target population of nine million people. It has a palliative care unit with a waiting room, two offices, 12 bedrooms for up to 16 inpatient beds, and an area where families can stay.

Our teams consist of 54 health professionals (physicians, nurses, social workers, psychologists, etc.) and 40 volunteers.

The main current activities of the PAMP-FF are:

1) Palliative care to the community

   All services provide outpatient care, day care, inpatient care and home care. They each provide free care to 200-300 new patients each year; 95% are cancer patients, 20-30% are permanently in treatment; and the average length of treatments is 97 days. The service runs around the clock, seven days a week, with nursing care continuously available. Medical care is available Monday to Friday from 9am to 5pm, while on Saturdays, Sundays and holidays only medical visits are available.

2) Community education

3) Research: epidemiological studies with an online database accessible for everyone that wishes to use it

4) Professional education:

   - annual training courses for volunteers in palliative care; 28 hours in length;
   - clinical rotations for health professionals and concurrently for physicians; two years in length;
   - residency for physicians, nurses and psychologists; three years in length;

- university-affiliated annual courses for physicians, nurses and psychologists;
- online palliative care courses for physicians and nurses, with optional bedside practice;
- palliative care module for oncologists, Universidad Católica Argentina, Buenos Aires city;
- Cursos en colectivo (CeC, bus-rounds), providing interdisciplinary theoretical and practical activity for primary care physicians and nurses; 1.5 days (14 hours) in length; three to four per year. The activity takes place in a bus or bus-round visiting the patients where they are – home or institution;
- Elective study by medical students of palliative care in their fourth, fifth and sixth years.

Level of support from the existing health system

The public health system is responsible in each institution for most of the human and all the material resources needed for the care of patients and families. The Fundación FEMEBA pays or supplements the wages of 19 people working in the different teams.

Innovations to highlight

Degree teaching in a medical school and the CeCs (bus-rounds) resulted from adapting both the content and teaching methods to the needs of medical students and primary healthcare professionals. Mobile teams to train and support primary healthcare providers were planned for 2012.

Patients and families in a tango session/meeting

Patient and physician

United Kingdom

St. Giles Hospice

Description of the model

St. Giles is an independent voluntary sector organisation (a charity). It offers specialist palliative care services via a mixed professional-volunteer model as indicated by the ratio of approximately 240 paid staff to 1,200 volunteers. Running costs are £8 million per annum. The specialist focus has led to a predominantly medical model of care, although this is beginning to be reconsidered in line with other United Kingdom hospices.

Services comprise a community team of specialist nurses, an end of life home care service, day hospice and two day therapies centres, two inpatient facilities, family support and bereavement counselling, and lymphoedema clinics.

Level of support from the existing health system

Approximately 40% of funding is derived from grants or contracts originating within the National Health Service. This financial support has not traditionally been attached to a particular part of the hospice's services; however this may change with the outcome of the United Kingdom government's 2011 spending review on palliative care. The remaining 60% is derived from the voluntary giving of the local community and the commercial operations of subsidiary companies.

Day-to-day service delivery is well integrated into the local health economy, especially with the statutory primary healthcare teams operating within the community. Referrals are generated principally by statutory healthcare services.

Innovations to highlight

Current innovations are developing from the recognition that engaging with local communities, promoting well-being, and a supportive care approach will be needed in the future. The projections of future social and health demographics, coupled with a lack of professional carers, means our focus is shifting towards building resilience and coping within our local community. For example, we are working with schools and a prison, seeking to support those communities in understanding loss and developing healthy internal responses, built on their own resources rather than making bereavement an illness to be treated by professionals.

We are using our day therapies centres to encourage personal contact, both social and therapeutic, and to enhance personal well-being and resilience. This also benefits our specialist services by ensuring that good supportive care is available so that specialist services can focus on those with the most complex needs.

Sustainability

It is likely that in the future statutory funding will be more closely tied to the specialist elements of the hospice's services. Supportive care is likely to involve more volunteer carers and to be funded predominantly by charitable income from two differing streams: diversification of commercial activities, and supporting those receiving supportive care to raise income to pay for those services.

Meanwhile, an increasing national emphasis on the role of competition in healthcare provision looks set to challenge the future delivery and sustainability of all our services. Palliative and end of life services are now part of a national strategy in the UK and are increasingly being provided outside of stand alone community hospices and in National Health Service Hospitals. Hospices will need to further integrate into the healthcare system and prove their value to the overall system in the coming years.

Chapter 6

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

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[44,45a,45b] have estimated the cost of care in the last year of life at between 25-30% of all medical expenditures. The US Medicare programme for those over 65 years spent a total of $484 billion US dollars in 2009, including $12 billion for hospice care. Palliative care outside of hospices in the USA is mostly hospital-based consultancy services. There are reportedly 1,568 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 just 34% 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 utilisation 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 5).

Philanthropic support

Many charitable organisations have a history of supporting hospice and palliative care development. Of the three that have been most prominent only one, Open Society Foundations, is currently active:

Open Society Foundations, International Palliative Care Initiative – Palliative care is a holistic healthcare 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.
www.soros.org/topics/palliative-care

The Robert Wood Johnson Foundation (RWJF) – From 1995 to 2003 the RWJF funded a number of initiatives in the United States to increase public awareness and develop palliative care as a discipline. Over 100 million US dollars was spent in this effort. After significant progress the programmatic emphasis on palliative care was discontinued.

The Diana Princess of Wales Memorial Fund – Between 2000 and 2011, the Diana, Princess of Wales Memorial Fund gave £11,978,383 in grants to organisations working to ensuring that palliative care is integrated into the care and treatment of people living with HIV/AIDS, cancer and other life-limiting illnesses in sub-Saharan Africa. After distributing £100 million the fund ended its existence at the end of 2012.

In 2008, a review of all donor organisations that support palliative care was done by Wright, Lynch, & Clark[46].

Bilateral support

Government support for international health includes some support for palliative care and related healthcare services. The largest of these agencies includes the Global Fund, the President's Emergency Plan for AIDS Relief (PEPFAR), the United Kingdoms Department for International Development (DFID), and individual country commitments to palliative care development. Exact funds committed towards palliative care are not available; however in the original PEPFAR law 15% was to be earmarked for palliative care. Global Fund funding for palliative care has largely been restricted to palliative care for HIV and TB programmes.

Research support

Every specialised component of healthcare 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 Center (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. (www.eapcnet.eu/Themes/Research.aspx).
- The Canadian Institutes of Health Research have made a substantial commitment to palliative and end of life research. For more information go to: www.cihr-irsc.gc.ca/e/27756.html.
- 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 healthcare professionals (www.duke-nus.edu.sg/research/centers/lien-centre-palliative-care).
- The African Palliative Care Research Network was formed in 2011 to focus specifically on building a research base for improving palliative care in the African context. www.africanpalliativecare.org/index.php?option=com_content&view=article&id=84&Itemid=4

Educational resources

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

Health Condition	Policy/managerial guidance	Education	Medicine availability	Clinical guidelines	Strategies
Cancer	Palliative Care (2007)	None	Cancer Pain Relief: A Guide to Opioid Availability (1996)	Cancer pain relief and palliative care in children (1998)	
	A community health approach to palliative care for HIV/AIDS and cancer patients in Sub-Saharan Africa (2004)		See below: Ensuring Balance	Cancer Pain Relief: With a guide to opioid availability (1996)	2008–2013 Action plan for the global strategy for the prevention and control of non-communicable diseases
	Planning and Implementing Cervical Cancer Prevention and Control Programmes (2004) National cancer control programmes: policies and managerial guidelines, a handbook (2002) National cancer control programmes: policies and managerial guidelines, a handbook (1992)			Cancer pain relief (1986)	
HIV/AIDS	Integrated management of adolescent and adult illness: interim guidelines for first-level facility health workers: palliative care: symptom management and end of life care (in press)	Integrated Management of Adult Illnesses, palliative care: symptom management and end of life care (2004)	See below: Ensuring Balance	Palliative Care for People Living with HIV/AIDS (2006) EURO	Global health sector strategy on HIV/AIDS 2011–2015

The pain management component contained in *Cancer pain relief and palliative care* has been superseded by *WHO guidelines on the pharmacological treatment of persisting pain in children* with medical illnesses listed on page 66.

Health Condition	Policy/managerial guidance	Education	Medicine availability	Clinical guidelines	Strategies
	Integrated management of adolescent and adult illness: interim guidelines for first-level facility health workers at health centre and district outpatient clinic: general principles of good chronic care (in press) Integrated management of adolescent and adult illness: interim guidelines for first-level facility health workers at health centre and district outpatient clinic: acute care (in press) Integrated Management of Adult Illnesses, palliative care: symptom management and end of life care (2004) A community health approach to palliative care for HIV/AIDS and cancer patients in Sub-Saharan Africa (2004) AIDS: palliative care (2000)			HIV/AIDS treatment and care: WHO protocols in CIS countries (2004)	
TB	See HIV/AIDS	See HIV/AIDS	See below: Ensuring balance	See HIV/AIDS	The Stop TB Strategy (2006). Strategy for the Prevention and Control of Chronic Respiratory Diseases (2002).
Pediatrics				WHO Guidelines on Persistent Pain in Children	
Old age	Palliative care for older people: better practices (2011) EURO	None	See below: Ensuring Balance	None	Madrid Plan of Action on Ageing:
	The end of life: unknown and unplanned? (2007) EURO				
	What are the palliative care needs of older people and how might they be met? (2004) EURO. Better palliative care for older people (2004) EURO. The solid facts: palliative care (2004) EURO				

Health Condition	Policy/managerial guidance	Education	Medicine availability	Clinical guidelines	Strategies
Chronic non-communicable diseases (except cancer)	None	None	See below: Ensuring Balance	None	See NCD Action Plan above.
Palliative care and primary healthcare	Integrated management of adolescent and adult illness: interim guidelines for first-level facility health workers at health centre and district outpatient clinic: general principles of good chronic care (in press)	None	See below: Ensuring Balance	None	Everybody business: strengthening health systems to improve health outcomes : WHO's framework for action (2007).
	Integrated management of adolescent and adult illness : interim guidelines for first-level facility health workers at health centre and district outpatient clinic : acute care (in press)				
	Integrated management of adolescent and adult illness: interim guidelines for first-level facility health workers (2004)				
General	None	None	Ensuring balance in national policies on controlled substances – Guidance for availability and accessibility of controlled medicines (2011)	Symptom relief in terminal illness (1998)	

The Worldwide Palliative Care Alliance has available the following reference documents: www.thewpca.org/resources

Palliative Care Toolkit: Improving care from the roots up in resource-limited settings

The Palliative Care Toolkit 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:

Spanish

Portuguese

Mandarin

Russian

Swahili

French

Bengali

Vietnamese

Training Manual for the Palliative Care Toolkit

The Training Manual was produced to accompany the toolkit. It contains structured teaching modules and resources which can help others use the toolkit. Available in the following languages:

French

Spanish

Portuguese

Mandarin

Bengali

Advocacy Toolkit

This toolkit highlights the key advocacy tools that are of relevance to hospice and palliative care organisations who wish to develop their advocacy work. It also provides examples of how these tools have been used and have worked in practice.

An introduction to resource mobilisation

This document provides information about effective fundraising. It was produced by the Resource Alliance for the Worldwide Palliative Care Alliance membership.

Palliative Care Association Toolkit

This toolkit is to support the development of national hospice and palliative care associations. It is presented in three parts, each of which has its own web page portal. Each section begins with an actual association-building vignette from palliative care leaders around the world. These real-life examples are followed by a variety of tools, definitions, references and other resources to round out the challenge of association building.

Go to www.thewpca.org for additional resources or to join for free.

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

Flinders University – Adelaide, South Australia
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
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
www.lancs.ac.uk/coursesearch/pg-course.php?course_id=015245
Doctorate in Palliative Care

University of Cape Town, South Africa
School of Public Health and Family Medicine
www.uct.ac.za
Diploma in Palliative Medicine
Masters of Philosophy in Palliative Medicine

University of Cardiff – Wales, United Kingdom
www.pallium.cardiff.ac.uk
Masters in Palliative Medicine
Masters in Palliative Care

University of Edinburgh – Scotland
Norwegian University of Science and Technology – Trondheim, Norway
European Palliative Care Research Network
www.ntnu.edu/prc?EuropeanPalliativeCareResearchNetwork
Doctorate in Palliative Care Research

An international listing of education and certificate programmes in palliative care is maintained by the International Association for Hospice and Palliative Care at:
www.hospicecare.com/global-palliative-care/global-directory-of-education-programs

Chapter 7 What is the way forward?

Access to palliative care, including access to pain relief, is a human right. It is highly effective at relieving the pain and suffering of people living with and affected by life-limiting illness, greatly enhancing their ability to live to the fullest up until the end of life. With an ageing world population and ever-increasing incidence of communicable and non-communicable diseases, the need for palliative care is increasing. Yet, millions of people worldwide cannot access this type of care, resulting in grave suffering.

This suffering is unnecessary. In each world region, there are countries that have shown how palliative care can be made available to those who need it and without adding new healthcare costs. Countries must learn from the innovations these countries have introduced to integrate palliative care into health and community-care systems and ensure the availability of controlled medications such as oral morphine.

The following steps will help to ensure access to palliative care for all those that need it:

- **Reviewing and improving the evidence base**
  A comprehensive review needs to be undertaken to map the evidence base around palliative care. This should include examining evidence of its cost-effectiveness and cost efficiency, its impact on community and health systems, and its outcomes for patients, caregivers and healthcare workers. A research agenda should be developed and funded to fill remaining gaps in evidence. Special attention should be afforded to populations such as children, older people and marginalised groups.

- **Reviewing and developing guidance**
  A comprehensive analysis needs to be undertaken to identify gaps in existing guidance on palliative care across levels of care in health and community systems and disease groups. In particular, it should examine whether adequate guidance is available for policy makers, public health services, civil society care providers and informal caregivers. The review should also examine what technical support is currently provided and whether this is adequate.

- **Scale-up, leadership and accountability**
  A major scale up of palliative care services and integration within healthcare systems is needed to ensure all who require them have access. To ensure coordination among agencies at all levels, a global task force should be set up with a clear division of labour to develop a strategy for such a scale up that includes specific targets and measurable benchmarks.

Specific recommendations

Technical agencies

- Review current guidance on palliative care for all life-limiting illness and address the gaps. This should include the development of new pain management guidelines and a strategy for integration of palliative care into healthcare systems across disease groups and levels of care.
- Monitor progress in palliative care development at the national and global level.
- Work with countries to review existing national health, HIV and non-communicable disease strategies and provide technical support to ensure comprehensive integration of palliative care into these strategies, including access to opioid analgesics.
- Global Fund needs to ensure appropriate technical guidance and assistance is given for inclusion of palliative care within GF proposals.
- INCB should reinforce its efforts to ensure that countries guarantee the 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 palliative care, and promoting palliative care educational development.

National governments

- Develop and implement a comprehensive budgeted action plan to scale up access to palliative care services for all those in need and integrate them into health and community-based support systems.
- Ensure that palliative care is integrated into appropriate national health and disease-specific policies. This should include costing of palliative care components and allocation of budget means. Clinical palliative care guidelines and standards should be developed and adopted.
- Take measures to overcome existing barriers to access to essential palliative medicines, especially oral opioid analgesics, for people with life-limiting illness. Countries should use WHO's palliative care guidance including Ensuring Balance etc. Existing medicine laws and regulations should be reviewed and amended when imbalanced or overly restrictive.
- Monitor progress in the development of palliative care at the national level, including consumption of opioids, accessibility to services, including for marginalised or vulnerable groups, and quality of care.

- Integrate hospice and palliative care education and training into mandatory undergraduate and more in-depth postgraduate curricula of medicine, nursing, social science, and other disciplines, especially for those seeking specialty recognition or that work with significant numbers of people with life-limiting conditions. Continuing professional education should include palliative care content.
- Develop and implement training programmes as well as support and supervision systems for non-professional community healthcare workers and carers.
- Ensure people living with life-limiting conditions, their carers and health professionals are consulted in the development of palliative care-related policies and services.

Bilateral donors, funders and foundations

- Ensure allocation of funds to palliative care as a fundamental component of the healthcare system and a human right for people living with life-limiting conditions and their carers.
- Ensure monitoring and evaluation of funded programmes include assessment of access to palliative care and the quality of life of people living with life-limiting conditions.

Summary and conclusion

We began this report by saying we would address the following questions:

- What is palliative care?
- Why is palliative care a human rights issue?
- What are the main diseases requiring palliative care?
- What is the need for palliative care?
- What are the barriers to palliative care?
- 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?

Palliative care has been defined and an argument for palliative care as a human rights issue has been framed.

The major diseases requiring palliative care were identified through a Delphi analysis. This analysis is limited by the typology used in the WHO Global Burden of Disease report. Undoubtedly there are additional diagnoses with relatively smaller numbers that do not appear in this report, such as amyotrophic lateral sclerosis, which do need palliative care. However, these major diseases represent the vast majority of those who will benefit from palliative care.

The need for palliative care has been estimated to be approximately 20,245,772 individuals out of 54,591,143 deaths from all causes in 2008, the most recent year for which the WHO has global mortality data. This represents just over 37% of all deaths from all causes. This percentage will vary considerably from country to country based on demographics and causes of death.

We note that this is a lower level estimate based on symptom prevalence. It is important for readers to understand that this is an estimate of the need for palliative care at the end of life. The WHO definition of palliative care calls for palliative care from diagnosis of a life-threatening illness to death and bereavement. Others will benefit from palliative care prior to their year of death, which would increase this number significantly. There are always a number of family members for each person who faces a life-threatening illness that would also be recipients of palliative care both during and after the death of the person.

In many countries palliative care is provided at primary, secondary, and tertiary levels such that some patients with a relatively low symptom burden can be managed by primary care systems with basic education in palliative care; basic education which all health professionals should receive in their training. Most will need secondary palliative care from providers trained to routinely provide this care. A smaller number with difficult symptoms, physical or psychological, will benefit from highly specialised palliative care services. Clearly the need for palliative care each year is great and will continue to grow in the decades ahead as the world population continues to grow older.

Many barriers continue to limit access to palliative care and appropriate symptom relief. We used the WHO public health model to identify policy barriers, education barriers, medicine availability barriers, and implementation barriers. We also discussed psychological, social, cultural, and financial barriers.

A study mapping levels of palliative care development was included to provide a picture of where palliative care is currently available and at what levels of development. We also included estimates of numbers of palliative care providers worldwide and those served by existing teams to highlight the enormous gap in access to needed palliative care. Current providers are meeting only about 14% of the need defined in this document.

Seven case studies of exemplary palliative care programmes in all major parts of the world are described including descriptions of service provision, levels of support from the existing healthcare system, innovations, and sustainability.

The meagre resources devoted to palliative care including government support, philanthropic resources, voluntary and community support, educational programme development, and limited research support is described.

This document can serve as a baseline, against which to make measurements, in order to advocate for increased access to palliative care.

All in all, this publication describes the need for palliative care globally and the enormous gap that exists in meeting that need. In spite of the success of palliative care development over the past 40 years in the developed world there is so much more to do in the developing world. Our efforts to expand palliative care need to focus on bringing relief of suffering and the benefits of palliative care to those with the least resources. This will take courage and creativity as we learn from each other how to integrate palliative care into existing but very limited healthcare systems. Much of our success will depend on the involvement of communities in caring for their members using the new knowledge and skills that quality palliative care education can offer.

Appendix 1 Methodology for Global Atlas of Palliative Care at the End of Life

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

Chapter 1: From published articles, and data on diagnoses requiring palliative care came from a Delphi Study conducted by WHO.

Chapter 2: For estimates of the need for palliative care by diagnosis we used the Delphi Study and published WHO mortality and population estimates (Global burden of disease based on 2011 estimates).

Chapter 3: Published literature on barriers and for opioid usage data used INCB data summarised by the WHO Access to Controlled Medicines Programme. This data is compiled by the Pain and Policies Study Group at the University of Wisconsin in cooperation with the International Narcotics Control Board. The data is published online at: http://ppsg-production.heroku.com

Chapter 4: We contracted with Thomas Lynch, PhD to update the published report on "Mapping levels of palliative care development: a global view." We used the Help the Hospices Database for the number of providers currently providing specialist palliative care services. This database is the most complete database currently in existence and is supplemented by several country-specific databases such as the National Hospice & Palliative Care Organization database in the US. Population data was gathered from United Nations Data. A ratio of services to base population was calculated.

The article this is based on has the following references:

Wright, M Wood, J Lynch, T Clark, D. Mapping levels of palliative care development: a global view. *J Pain & Symptom Mgmt 2008* 35(5): 469-85.

Lynch T, Connor S, & Clark D. Mapping levels of palliative care development: A global update. *J Pain & Symptom Mgmt* 2013; 45(6): 1094-1106.

The Help the Hospices international database is an online database that can be accessed at: www.helpthehospices.org.uk/about-hospice-care/international/find-an-overseas-service

The US directory of providers can be found at: https://netforum.nhpco.org/eWeb/DynamicPage.aspx?Site=NHPCO&WebKey=a9338cdd-546a-42f5-9061-6b91dbdb31da

Children's palliative care service estimates came from a related project developed by the International Children's Palliative Care Network. This data is published in the following article:

Knapp C, Woodworth L, Wright M, Downing J, Drake R, Fowler-Kerry S, Hain R, Marston J. Pediatric palliative care provision around the world: A systematic review. *Pediatric Blood & Cancer 2011;* 57: n/a. doi: 10.1002/pbc.23100.

Estimates of numbers of patients served has been done using sampling data from several regions including the US, Sub-Saharan Africa, Europe, and India. We computed an average number of admissions per provider. We then multiplied that times the estimate of providers worldwide and by region to calculate an estimate of total palliative care patients that died under specialist palliative care services. We note that an additional but unknown number of patients received a partial palliative care service from non-specialised providers.

The publication that provides data on US hospice patient deaths can be accessed at: www.nhpco.org/hospice-statistics-research-press-room/facts-hospice-and-palliative-care

Chapter 5: We used a combination of published case reports and structured interviews to describe different models of palliative care programming. These reports highlighted innovations in the financing and sustainability of these models.

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: Summarises the previous sections and provides narrative conclusions.

Appendix 2 Additional sections on the mapping levels of palliative care development report – Background, Methods, Changes Over Time, Limitations and Discussion

Background

In 2006, Professor David Clark and Dr. Michael Wright from the International Observatory on End of life Care (IOELC) presented a report that measured palliative care development in all countries of the world and classified them according to levels of palliative care development. The IOELC built on a basic description that had been produced earlier by the Hospice Information Service but attempted to build more depth into the analysis by developing 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).

The work was subsequently published in the *Journal of Pain and Symptom Management*[36] and has been heavily cited as well as adopted as a tool for international palliative care advocacy. At the same time it was clear that the rankings might 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 has been repeated in 2011, with some new criteria. Within the typology changes have been made to the criteria for level of palliative care development in groups 3 and 4 and these have been sub-divided to produce two additional levels of categorisation (groups 3a and 3b/4a and 4b)[41].

Methods

The methods used for the project were twofold. First, data about the level of palliative care development within each country in the world was collected from the following sources: published articles in peer reviewed and professional journals; books and monographs; palliative care directories; palliative care websites; data provided by the European Association for Palliative Care (EAPC) Task Force for the Development of Palliative Care in Europe[47]; IOELC reviews and databases; grey literature and conference presentations; and, in particular, the opinions of 'key persons' in the field of palliative care. Data were analysed against the typology's key elements and each country was allocated to one of the six categories on the basis of its level of palliative care development.

Changes over time

In 2006, 115 of the world's 234 countries (49%) had established one or more hospice-palliative care services; in 2011, 136 of the world's 234 countries (58%) had one or more hospice-palliative care services established – an increase of 21 countries (+9%) from the previous project. In 2006, 156 countries (67%) were actively engaged in either delivering a hospice-palliative care service or developing the framework within which such a service could be delivered; in 2011, there had been a slight increase in this number to 159 countries (68%) – a rise of +1%.

In 2006, there was no known palliative care activity in 78 of the world's 234 countries (33%); by 2011, this figure had decreased by a total of three countries (-1%) to 75. The number of countries that were demonstrating capacity-building potential in 2006 was 41 (18%); by 2011, this number had decreased by a total of 18 countries to 23 – a decrease of -8%. Countries with localised hospice-palliative care provision in 2006 totaled 80 (34%); in 2011 the combined number of countries in categories 3a and 3b totalled 91 (39%) – an increase of 11 countries (+5%). Finally, the division of group 4 indicates that while 27 countries (12%) are now approaching integration with mainstream health service providers, only 18 countries (8%) have actually achieved this. In 2011, the total number of countries in category 4 was 45 (19%), as opposed to 35 (15%) in 2006 – an increase of 10 countries (+4%).

Table 1
Gross changes in the number of countries in each category

Group	2006	2011	Change=n	Change=%
Group 1	78 (33%)	75 (32%)	-3	-1%
Group 2	41 (18%)	23 (10%)	-18	-8%
Group 3	80 (34%)	91 (39%)	+11	+5%
Group 4	35 (15%)	45 (19%)	+10	+4%

Table 2
Changes in palliative care direction by country 2006–2011

Group	Changes in palliative care direction COUNTRY 2006–2011 (+/-)
Group 1	UZBEKISTAN (- from category **2**)
Group 2	MONTENEGRO (+ from category 1)/ALAND ISLANDS (- from category **3**) AZERBAIJAN (- from category **3**) HONDURAS (- from category **3**)
Group 3a	ANGOLA (+ from category **1**) BAHRAIN (+ from category **2**) BELIZE (+ from category **2**) BRUNEI (+ from category **2**) ETHIOPIA (+ from category **2**) GHANA (+ from category **2**) IRAN (+ from category **2**) KUWAIT (+ from category **2**) LEBANON (+ from category **2**) LESOTHO (+ from category **2**) MALI (+ from category **1**) MOZAMBIQUE (+ from category **2**) NAMIBIA (+ from category **2**) NIUE (+ from category **1**) PARAGUAY (+ from category **2**) RWANDA (+ from category **2**) SAINT LUCIA (+ from category **2**) SUDAN (+ from category **2**)
Group 3b	COTE D'IVORIE (+ from category **2**) TURKEY (+ from category **2**)/ ARGENTINA (- from category **4**)
Group 4a	CHINA (including Taiwan) (+ from category **3**) LUXEMBOURG (+ from category **3**) MACAU (+ from category **3**) MALAWAI (+ from category **3**) PUERTO RICO (+ from category **2**) SERBIA (+ from category **3**) SLOVAKIA (+ from category **3**) TANZANIA (+ from category **3**) URUGUAY (+ from category **3**) ZAMBIA (+ from category **3**) ZIMBABWE (+ from category **3**)
Group 4b	(New categorisation)

Table 3
Changes in palliative care direction by region 2006–2011

Group	Changes in palliative care direction REGION 2006–2011 (+/-)
Group 1	1 x **CEE/CIS** (- from category **2**)
Group 2	1 x **CEE/CIS** (+ from category **1**)/ 1 x **EUROPE** (- from category **3**) 1 x **CEE/CIS** (- from category **3**) 1 x **AMERICAS/CARIBBEAN** (- from category **3**)
Group 3a	2 x **AFRICA** (+ from category **1**) 7 x **AFRICA** (+ from category **2**) 5 x **MIDDLE EAST** (+ from category **2**) 1 x **ASIA PACIFIC/OCEANIA** (+ from category **1**) 3 x **AMERICAS/CARIBBEAN** (+ from category **2**)
Group 3b	1 x **AFRICA** (+ from category **2**) 1 x **EUROPE** (+ from category 2)/ 1 x **AMERICAS/CARIBBEAN** (- from category 4)
Group 4a	2 x **ASIA PACIFIC/OCEANIA** (+ from category **3**) 1 x **EUROPE** (+ from category 3) 4 x **AFRICA** (+ from category **3**) 1 x **AMERICAS/ CARIBBEAN** (+ from category **2**) 1 x **AMERICAS/CARIBBEAN** (+ from category **3**) 2 x **CEE/CIS** (+ from category **3**)
Group 4b	

Limitations

This approach has accompanying limitations; for example, there was an absence of data for some countries. Also, the way in which services are counted is problematic because two systems operate in tandem: services in some continents are counted by provider, irrespective of the number of services; in Europe, they are counted by type (for example, home care, day care, inpatient units, hospital teams). Although this allows a degree of comparability for services in the countries of Europe and within and across the other five continents, it also inhibits any comparable worldwide analysis. In addition, listing services by provider is by no means foolproof and could be a source of bias as a country with few but large-scale provider organisations would show a lower ratio of services per capita compared with a country having several small providers. We have attempted to address these issues by listing the number of providers and services in the same category of data under the heading 'services/providers', and attempting to glean clarification from 'key persons' and local palliative care experts. Since a service is the primary unit of care delivery the map includes mainly specialist palliative care services or where only one provider was available they are counted as a service. We have not included home-based care or long-term care providers that may provide some elements of palliative care but who are not primarily delivering formal palliative care.

The vast majority of data relating to palliative care development was self-reported by 'key persons' in each respective country, and this is acknowledged by the authors as a potential weakness as data provided in this way may be subject to bias or inaccuracy; in the limited number of cases when this was explicitly apparent, the perceived anomaly has been highlighted.

A further limitation to the project was that respondents often experienced difficulty in choosing between the divided categories 3a or 3b/4a or 4b. Some respondents suggested that their country 'did not fit into any category', that their country was 'somewhere on the border' between two categories, or that 'strengths and limitations' existed within each sub-category. This situation was reflected in a number of countries in Central and Eastern Europe/Commonwealth of Independent States (CEE/CIS), where national palliative care associations had been formed but because of financial problems and political changes that resulted in inconsistent public health policy, the progress of palliative care remained 'very slow'. Respondents from the Americas/Caribbean also experienced some difficulty in determining between the newly divided categories; for example, the respondent from Panama stressed that her country was 'not 3a at all, but cannot be categorised as 3b either'.

In the Asia Pacific and Oceania Region, the respondent from Nepal experienced some difficulty in choosing between group 3a and 3b, while the respondent from Australia found differentiating between group 4a and 4b somewhat problematic. A number of Western European countries (for example, Austria, Denmark, Netherlands and Spain) also had difficulty in categorising themselves in either category 4a or

4b, suggesting that they often 'scored differently for the different items' and were therefore 'somewhere in between'. In the Africa Region, the respondent from South Africa proposed another sub-category within category 4 to further refine the typology. All in all self assessments are subjective and their use may lack accuracy. In addition we acknowledge that while we did our best to identify all countries with services we likely have missed some in the 2006 report and likely there are services operating in 2011 that we were unaware of at the time of this report.

Discussion

Results from this mapping exercise of global palliative care development indicate that since 2006, there has been an increase in the number of countries of the world that have established one or more hospice-palliative care services (+9%), although only a slight increase has occurred in the total number of countries actively engaged in either delivering a hospice-palliative care service or developing the framework within which such a service can be delivered (+1%). In sum, it appears that since 2006, a total of 21 countries (9%) have moved from group 1/2 (no known activity/capacity building) into groups 3/4 (some form of palliative care provision). It should be acknowledged however that, within the context of these results, there are many instances where palliative care remains inaccessible to the majority of a country's population.

A regional analysis of palliative care development between 2006 and 2011 indicates that the most notable regions involved in the change of direction from group 1/2 (no known activity/capacity building) to group 3a (isolated provision) are Africa (+9 countries) and the Middle East (+5 countries); another region involved in this change of direction is Americas/Caribbean (+3 countries). In the Middle East, a good example of progress is provided by Lebanon, which moved from group 2 to 3a as a 12-bed inpatient palliative care unit had been established by a religious organisation in Beyrouth. In Africa, Angola moved from group 1 to 3a because the African Palliative Care Association (APCA) conducted an exploratory study there and initiated some palliative care contacts that resulted in one service being established. Ghana also moved from group 1 to 3a because a national palliative care association was formed and a number of palliative care services have since been established. Ethiopia, Namibia, Rwanda and Sudan all moved from group 2 to 3a because a palliative care infrastructure had been developed and isolated palliative care services provided, albeit at a low level; Cote d'Ivoire moved from group 2 to 3b for the same reason, although progress there is reported as slightly greater than in other countries of the region.

Another change in direction occurred from group 3 to 4a, with Africa once again being the most prominent region (+4 countries). Countries such as Malawi, Tanzania, Zambia, and Zimbabwe changed direction because of the work APCA and other partners have done to develop

and scale up palliative care in those countries; APCA suggest that these countries have made 'tremendous progress' in recent years and envisage them being re-categorised to group 4b (advanced integration) in the near future. Other African countries believed to be close to moving from group 3 to 4 include Botswana, Cameroon, Morocco and Nigeria. However, the impact that the withdrawal of support by The Diana, Princess of Wales Memorial Fund from Africa in 2012 will have on the continued development of palliative care in the region is as yet unknown.

Two countries from CEE/CIS moved from group 3 to group 4a. Slovakia was re-categorised for a number of reasons: a number of hospices had opened in the country; hospice beds were now available in hospitals and teaching hospitals; palliative care was gradually being implemented into postgraduate education for physicians and undergraduate education for nurses; a Chair of Palliative Medicine at Slovak Medical University had been established; there was good availability of morphine; and there was a national association of palliative care (Slovakian Association of Hospice and Palliative Care) plus another organisation, the Chapter of Palliative Care of Slovak Society for Study and Treatment of Pain, which covered the palliative care educational needs of both physicians and nurses. Serbia was re-categorised due to the impact of their three-year National Strategy for Palliative Care Development which would substantially increase the number of hospital/home-based palliative care teams and palliative care units throughout the country, provide education and training initiatives for both health professionals and the families of patients, improve the availability of oral morphine and other forms of opioids, and ultimately result in the integration of palliative care into the Serbian healthcare system.

In Western Europe, the respondent from Luxembourg re-categorised the country from group 3 to 4a due to an increase in the number of hospice and palliative care units and the substantial development of palliative care education and training initiatives in the country; progress has also been due to the introduction of a new law relating to palliative care that was introduced in 2009.

In the Americas/Caribbean, Uruguay re categorised from group 3 to 4a for a number of reasons: the number of hospice-palliative care services had increased; palliative care is now recognised in the National Health Programme; a Diploma in Palliative Care had been introduced into the State University along with undergraduate palliative care programmes in other universities; the national association was 'developing rapidly'; and the availability of opioids was described as 'good'. In contrast, although Argentina had made 'major advances in palliative care over the last 20 years', there was still only localised hospice-palliative care provision; 'great disparity' still existed in the palliative care that was provided, according to geography and differing levels of complexity and areas still existed where palliative care was inaccessible; as a result, Argentina re-categorised from group 4 to group 3b.

Appendix 3 Organisational resources

Organisations working in hospice and palliative care nationally with some international programs, or exclusively on international palliative care.

African Palliative Care Association
Kampala, Uganda
www.africanpalliativecare.org
APCA's mission is to promote and support affordable and culturally appropriate palliative care throughout Africa.

American Hospice Foundation
2120 L. Street NW, Suite 200
Washington, DC 20037
800-347-1413
www.americanhospice.org
The American Hospice Foundation supports programmes that serve the needs of terminally ill and grieving individuals of all ages.

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 organisations committed to alleviating suffering from life-threatening illness in the Asia Pacific region.

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.

Centers for Disease Control AIDS Information
www.cdc.gov/globalaids
A valuable international resource on HIV/AIDS.

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.

ehospice
www.ehospice.com

ehospice is the first globally managed news and information website and app on hospice, palliative and end of life care, bringing you the latest news, intelligence, commentary and analysis from the sector. At the touch of a button, you can access the expertise and experience of the global palliative care community.

European Association for Palliative Care

www.eapcnet.org

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.

Foundation for Hospices in Sub-Saharan Africa

www.fhssa.org

FHSSA, an affiliate of NHPCO, helps to generate resources and technical support for hospice organisations in sub-Saharan Africa, primarily through developing partnerships between USA and African hospice and palliative care programmes.

Help the Hospices

Hospice House
34-44 Britannia St
London WC1X 9JG
United Kindgom
+44 (0)20 7520 8200
info@helpthehospices.org.uk
www.helpthehospices.org.uk

Help the Hospices wants the very best care for everyone facing the end of life. It supports its members and other organisations as they strive to grow and improve end of life care throughout the UK and across the world.

Hospice Association of America

228 7th Street SE
Washington, DC 20003
202-547-7424
www.nahc.org/haa

A membership organisation within the National Association for Home Care that advocates for hospice care.

Hospice Foundation of America

1621 Connecticut Ave., NW
Suite 300
Washington, DC 20009
800-854-3402
www.hospicefoundation.org

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

International Association for Hospice and Palliative Care
www.hospicecare.com
Its 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 favorable policies around the world.

International Children's Palliative Care Network
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.

International Observatory on End of Life Care
www.lancaster.ac.uk/shm/research/ioelc
The aim of the International Observatory on End of Life Care is to undertake high-quality research, clinical studies, evaluation, education, advocacy and consultancy to improve palliative and end of life care for patients and family carers.

Latin American Association for Palliative Care
www.cuidadospaliativos.org
Its 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
1731 King Street
Alexandria, VA 22314
703-516-4928
www.nationalhospicefoundation.org
The national charity for end of life care in the United States.

National Hospice and Palliative Care Organization
1731 King Street
Alexandria, VA 22314
www.nhpco.org
703-837-1500
NHPCO is the largest non-profit membership organisation representing hospice and palliative care programmes and professionals in the United States.

Open Society Foundations
International Palliative Care Initiative
400 West 59th Street
New York, NY 10019, U.S.A.
1-212-548-0600
www.soros.org/initiatives/health/focus/ipci
The goal of OSFs' International Palliative Care Initiative is to improve end of life care for patients and their families, with a special focus on vulnerable populations including the elderly, children, and patients with cancer or HIV/AIDS.

Palliative Care Australia
Level 1
21 Napier Close
Deakin
ACT 2600
Australia
+61 2 6232 4433
pcainc@palliativecare.org.au
www.palliativecare.org.au
Palliative Care Australia is the peak national organisation representing the interests and aspirations of all who share the ideal of quality care at the end of life.

St. Christopher's Hospice
51-59 Lawrie Park Road
Sydenham, London SE26 6DZ
020 8768 4500
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 Palliative Care Alliance
www.thewpca.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 organisations and affiliate organisations supporting hospice and palliative care.

Journals

American Journal of Hospice & Palliative Medicine
Thousand Oaks, California: Sage Publications
http://ajh.sagepub.com

BMJ Palliative and Supportive Care
London, England: BMJ Publishing Group
http://spcare.bmj.com/site/about

Death Studies
New York: Routledge
www.tandf.co.uk/journals/titles/07481187.asp

European Journal of Palliative Care
Newmarket, England
www.ejpc.eu.com

Illness, Crisis, and Loss
Amityville, NY: Baywood Publishing Co.
www.baywood.com/journals/PreviewJournals.asp?Id=1054-1373

Indian Journal of Palliative Care
New Delhi, India
www.jpalliativecare.com

Journal of Hospice and Palliative Nursing
Hospice & Palliative Care Nurses Association
http://journals.lww.com/jhpn/pages/default.aspx

Journal of Pharmaceutical Care in Pain and Symptom Control
Informa Healthcare
http://informahealthcare.com/toc/wzzp/1/1

Journal of Pain and Symptom Management
New York: Elsevier.
www.elsevier.com/wps/find/journaldescription.cws_home/505775/description#description

Journal of Palliative Medicine
New Rochelle, NY: Mary Ann Leibert
www.liebertpub.com/publication.aspx?pub_id=41

Journal of Palliative Care
Montreal, Canada: Center for Bioethics – IRCM
www.criugm.qc.ca/journalofpalliativecare

OMEGA: The Journal of Death & Dying
Amityville, NY: Baywood Publishing Co.
www.baywood.com/journals/PreviewJournals.asp?Id=0030-2228

Palliative and Supportive Care
New York: Cambridge University Press
http://journals.cambridge.org/action/displayJournal?jid=PAX

Palliative Medicine
London, England: Sage Publications
www.sagepub.co.uk/journalsProdDesc.nav?prodId=Journal201823

Progress in Palliative Care
Maney Publishing – Leeds, UK
http://maneypublishing.com/index.php/journals/ppc

Supportive Care in Cancer
Springer Publishing, New York
http://link.springer.com/journal/520

Appendix 4 WHO collaborating centres on palliative care

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
www.iconcologia.net

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, India
Director: Dr Suresh Kuttierath Kumar
www.instituteofpalliativemedicine.org

WHO Collaborating Centre for Palliative Care and Older People
Department of Palliative Care, Policy and Rehabilitation
King's College London
Weston Education Centre, Cutcombe Road SE5 9RJ
London, England
Director: Irene Higginson
www.kcl.ac.uk/schools/medicine/depts/palliative

WHO Collaborating Centre for Palliative Care
Sir Michael Sobell House, Churchill Hospital
Headington OX3 7LJ Oxford, England
Director: Dr Bee Wee
www.sobellhospiceoxford.org

WHO Collaborating Centre for Pain Policy in Palliative Care
Pain & Policy Studies Group, Carbone Cancer Center
University of Wisconsin School of Medicine and Public Health
1300 University Ave, Suite 6152, Madison, WI 53706
Director: Dr James F. Cleary
www.painpolicy.wisc.edu

WHO Collaborating Centre for Training and Policy on Access to Pain Relief
Trivandrum Institute of Palliative Sciences, Pain & Palliative Care Center, S.U.T. Hospital, Pattom, 695 004 Kerala, Trivandrum India.
Director: Dr. M.R. Rajagopal.
www.tipsindia.org

Appendix 5 Hospice cost-effectiveness literature summary

A total of 16 articles were reviewed all of which were from work done in North America. Overall, the utilisation 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. For example, Campbell and colleagues (2004) found that hospice enrollment correlated with reduced Medicare expenditures among younger enrollees with cancer. 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 $2,309 per hospice user in the last year of life. Of particular significance, Pyenson et al. (2004) discovered that lower cost of care was not associated with shorter time until death. 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 healthcare providers and organisations (Penrod et al., 2006).

Only one study (Campbell et al., 2004) 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 (Wright et al., 2008; Zhang et al., 2009) also examined the effect of end of life discussions on cost of care. 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.

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Appendix 6 Methodology for estimating the number of people in need of palliative care

The estimates used 2011 mortality data from the WHO Global Health Estimates. Although the WHO definition states that palliative care should be provided early after the diagnosis of a life-limiting condition, this chapter assesses only the need for palliative care at the end of life in view of the fact that there is mortality data available for all countries. Therefore, this assessment provides low level estimates as they reflect only terminal care.

In order to identify the diseases (ICD 10) requiring palliative care at the end of life, WHO conducted two Delphi studies with external experts and did a subsequent internal review. The results were the following:

- **Diseases requiring palliative care for adults (population aged 15 years and above):** Alzheimer's disease and other dementias, cancer, cardiovascular diseases, cirrhosis of the liver, chronic obstructive pulmonary diseases, diabetes, HIV/AIDS; kidney failure; multiple sclerosis; Parkinson's disease; rheumatoid arthritis; drug-resistant tuberculosis.
- **Diseases requiring palliative care for children (population under age 15):** cancer, cardiovascular diseases, cirrhosis of the liver, congenital anomalies, endocrine, blood, immune disorders, HIV/AIDS, meningitis, kidney disease, neurological disorders, neonatal conditions, protein energy malnutrition.

Caution is needed when using only diagnoses for the assessment, because not all patients with a certain diagnosis are in need of palliative care. There are generally three groups of patients: those who have a palliative period of advancing progressive disease; those who have a stable or no disease, relatively few symptoms but then deteriorate or die suddenly; and those who suffer from chronic disease, where the disease is not clearly progressing, but who might have periods of progression and symptoms where they would benefit from palliative care and then periods of remission.[30]

Because it is not precisely known what the proportions are of those three groups of patients requiring palliative care, symptoms experienced in the last year of life can be used as indicator of palliative care needs.

The estimates in this chapter are based on pain prevalence as this is one of the most prevalent symptoms at the end of life for both adults and children suffering from malignant and non-malignant chronic conditions. In addition, pain relief for palliative care is considered an urgent humanitarian need requiring adequate medical care across all levels of the health system.

Review of pain prevalence evidence

With respect to symptom prevalence in adults, we have refined the pain prevalence data to some extent by disease. In addition to the original reference on pain by Higginson[30], probably the most useful source is the 2006 review of symptom prevalence across different non-cancer conditions[48]. This gives pain prevalence as:

- Cancer: 84%[30] 35-96%[48]
- Heart disease: 41-77%[30] 67%[30] 70%[49]
- Renal failure: 47-50%[48]
- Chronic obstructive pulmonary diseases: 34-77%[48] 67%[30]
- HIV/AIDS: 63-80%[50] 80%[51]
- Cirrhosis of the liver: 67%[52]
- Multiple sclerosis: 43%[50,51]
- Parkinson's disease: 82%[53,54]
- Alzheimer's disease and other dementias: 47%[55]
- Rheumatoid arthritis 89%[56]
- Diabetes mellitus 64%[57,58]
- Multi-drug-resistant tuberculosis 90%[59].*

* Estimate of the need of multi-drug-resistant tuberculosis palliative care is available only for the adult global population (153,000 per year) . Therefore, estimates stratified by gender, regions, age groups or income categories do not include deaths from this disease.

The estimated pain prevalence at the end of life for children dying from life limiting conditions is also based on a literature review and is estimated for the three disease categories as follows:

cancer: 80%[30]

progressive non-malignant: 67%*

HIV/AIDS: 55%[60]

Additional Assumptions from the Health Statistics and Informatics Department at WHO include the following:

- All estimated acute/sudden deaths from cardiovascular disease (33%) are removed from the disease group before applying the 67% of deaths with pain.
- For neonatal deaths, before applying the 67% pain prevalence, most deaths on the day of birth are removed from the disease group (25%). Of the remaining deaths, 75% are removed because they are avertable with resuscitation.
- For congenital malformations half of the congenital heart anomalies are removed from the disease group. This is an estimate of those children with treatable conditions or those without significant symptomatology.
- Endocrine disorders are excluded from the endocrine, blood, immune disorders group.

* As no information was found, it is assumed that pain prevalence in children dying from progressive non-malignant diseases is the same as in adults.

The template below summarises the method for estimating the number of people in need of palliative care (PC) at the end of life.

Disease categories/groups requiring palliative care at the end of life	Total Deaths from diseases requiring palliative care at the end of life Numeric (A)	Pain Prevalence at the end of life (%): B	Patients in need of palliative care at the end of life Numeric: C=AxB
CANCER			
Adults	7,786,470	84%	6,540,634
Children	83,282	80%	66,625
Total Cancer	**7,869,752**		**6,607,260**
HIV/AIDS			
Adults	1,373,267	80%	1,098,613
Children	217,684	55%	119,726
Total HIV/AIDS	**1,590,952**		**1,218,340**
PROGRESSIVE NON-MALIGNANT DISEASES			
Adults			
Alzheimer's disease and other dementias	673,454	47%	316,523
Cardiovascular diseases (excluding sudden deaths)	11,040,032	67%	7,396,821
Chronic obstructive pulmonary diseases	2,945,179	67%	1,973,270
Cirrhosis of the liver	961,060	34%	326,760
Diabetes mellitus	1,379,556	64%	882,915
Multiple sclerosis	18,130	43%	7,796
Kidney diseases	775,503	50%	387,751
Parkinson's disease	112,810	82%	92,504
Rheumatoid arthritis	58,614	89%	52,167
Drug-resistant tuberculosis	170,000	90%	153,000
Total PROGRESSIVE NON-MALIGNANT DISEASES	**18,134,342**		**11,589,511**
PROGRESSIVE NON-MALIGNANT DISEASES			
Children			
Cardiovascular diseases	107,932	67%	72,315
Cirrhosis of the liver	18,481	67%	12,382
Congenital anomalies (excluding 50% heart anomalies)	437,583	67%	293,180
Endocrine, blood, immune disorders excluding endocrine conditions	102,122	67%	68,422
Meningitis	220,384	67%	147,657
Kidney diseases	39,257	67%	26,302
Protein energy malnutrition	246,493	67%	165,150
Neurologicial conditions (excluding epilepsy)	40,258	67%	26,973
*Neonatal Conditions (see formula for excluded conditions)	255,633	67%	171,274
Total PROGRESSIVE NON-MALIGNANT DISEASES	**1,468,147**		**983,658**
Total Adults	**27,294,080**		**19,228,760**
Total Children	**1,769,114**		**1,170,011**
Grand Total	**29,063,194**		**20,398,772**

*Neonatal conditions formula: ((X-A-B*0.75)*0.75)-(C*0.75)
X=Neonatal conditions total deaths; A=Neonatal sepsis and infections
B=Birth asphyxia and birth trauma; C=Preterm birth complications

Table 1
Estimates of number of adults in need of palliative care at the end of life by WHO regions, disease categories, gender and age groups

		Disease categories			Males		Females		Both genders	
WHO regions	Total	HIV/AIDS	Cancer	Progressive non-malignant	15-59 years	60 years and above	15-59 years	60 years and above	15-59 years	60 years and above
World	19,228,760#	1,098,613	6,540,634	11,589,511	2,886,672	7,112,572	2,213,170	6,863,345	5,099,842	13,975,918
Africa	1,765,505	709,754	346,203	709,547	513,957	312,374	589,238	349,934	1,103,196	662,308
Region of the Americas	2,588,117	52,963	1,031,135	1,504,018	285,497	1,012,921	225,605	1,064,092	511,103	2,077,013
Eastern Mediterranean	939,923	27,723	266,588	645,612	156,941	351,566	127,541	303,873	284,483	655,440
European	4,168,927	73,941	1,618,526	2,476,460	448,172	1,653,538	253,299	1,813,916	701,472	3,467,455
South East Asia	4,143,432	172,662	1,008,689	2,962,080	809,583	1,466,556	566,426	1,300,865	1,376,010	2,767,421
Western Pacific	5,469,854	61,569	2,269,492	3,138,793	672,518	2,315,614	451,057	2,030,663	1,123,575	4,346,278

Table 2
Estimates of rates for adults in need of palliative care at the end of life (per 100,00 population)* by WHO regions, disease categories, gender and age groups

		Disease categories			Males		Females		Both genders	
WHO regions	Total	HIV/AIDS	Cancer	Progressive non-malignant	15-59 years	60 years and above	15-59 years	60 years and above	15-59 years	60 years and above
World	377.6	21.6	128.5	227.6	131.8	2,004.7	104.2	1,619.2	118.2	1,794.8
Africa	353.4	142.1	69.3	142.0	225.5	1,566.8	258.6	1,467.2	242.0	1,512.6
Region of the Americas	365.8	7.5	145.7	212.6	98.6	1,799.4	77.1	1,534.9	87.8	1,653.4
Eastern Mediterranean	234.1	6.9	66.4	160.8	84.1	1,856.1	72.4	1,539.7	78.4	1,694.7
European	561.5	9.9	218.0	333.6	159 .8	2,222.7	89.4	1,743.8	124.4	1,943.5
South East Asia	319.8	13.3	77.9	228.6	137.7	2,107.5	101.2	1,663.7	119.9	1,872.7
Western Pacific	378.5	4.3	157.0	217.2	108.9	2,002.5	77.3	1,577.1	93.6	1,778.4

Includes drug-resistant tuberculosis (153,000 deaths) for which there are only global figures
* See adult population estimates in table 5

Table 3
Estimates of number of children in need of palliative care at the end of life by WHO regions, disease categories, and gender

WHO regions	Total	HIV/AIDS	Cancer	Progressive non-malignant	Males	Females
World	1,170,011	119,726	66,625	983,658	604,393	565,618
Africa	573,848	108,686	15,571	449,589	295,838	278,009
Region of the Americas	57,405	1,492	6,644	49,268	31,398	26,007
Eastern Mediterranean	138,229	1,883	10,508	125,836	71,699	66,529
European	36,135	252	4,590	31,292	20,320	15,814
South East Asia	280,925	6,195	17,594	257,134	138,605	142,320
Western Pacific	83,466	1,214	11,715	70,536	46,530	36,936

Table 4
Estimates of rates for children in need of palliative care at the end of life per (per 100,00 population)# by WHO regions, disease categories, and gender

WHO regions	Total	HIV/AIDS	Cancer	Progressive non-malignant	Males	Females
World	63.4	6.5	3.6	53.3	63.3	63.5
Africa	160.4	30.4	4.3	125.7	163.6	157.1
Region of the Americas	24.8	0.7	2.9	21.3	26.6	23.0
Eastern Mediterranean	68.1	0.9	5.2	62.0	69.1	67.1
European	23.0	0.2	2.9	19.9	25.2	20.7
South East Asia	52.5	1.2	3.3	48.1	50.0	55.2
Western Pacific	23.0	0.3	3.2	19.5	23.9	22.0

Table 5
Estimates of child and adult population (in thousands) by WHO regions, gender and age groups

WHO regions	Total child population	Males	Females	Total adult population	Males		Females		Both genders	
		Under 15 years			15-59 years	60 years and above	15-59 years	60 years and above	15-59 years	60 years and above
World	1,846,255	954,955	891,299	5,092,000	2,189,558	354,788	2,123,769	423,885	4,313,327	778,673
Africa	357,785	180,832	176,952	499,595	227,924	19,936	227,882	23,850	455,807	43,787.70
Region of the Americas	231,076	117,879	113,196	707,569	289,430	56,292	292,519	69,326	581,950	125,619
Eastern Mediterranean	202,999	103,778	99,221	401,475	186,533	18,940	176,266	19,735	362,799	38,676
European	157,008	80,578	76,430	742,433	280,536	74,392	283,483	104,020	564,020	178,413
South East Asia	534,764	277,094	257,669	1,295,597	587,926	69,588	559,892	78,189	1,147,819	147,777
Western Pacific	362,621	194,792	167,829	1,445,328	617,205	115,637	583,723	128,762	1,200,929	244,399

See child population estimates in table 5

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