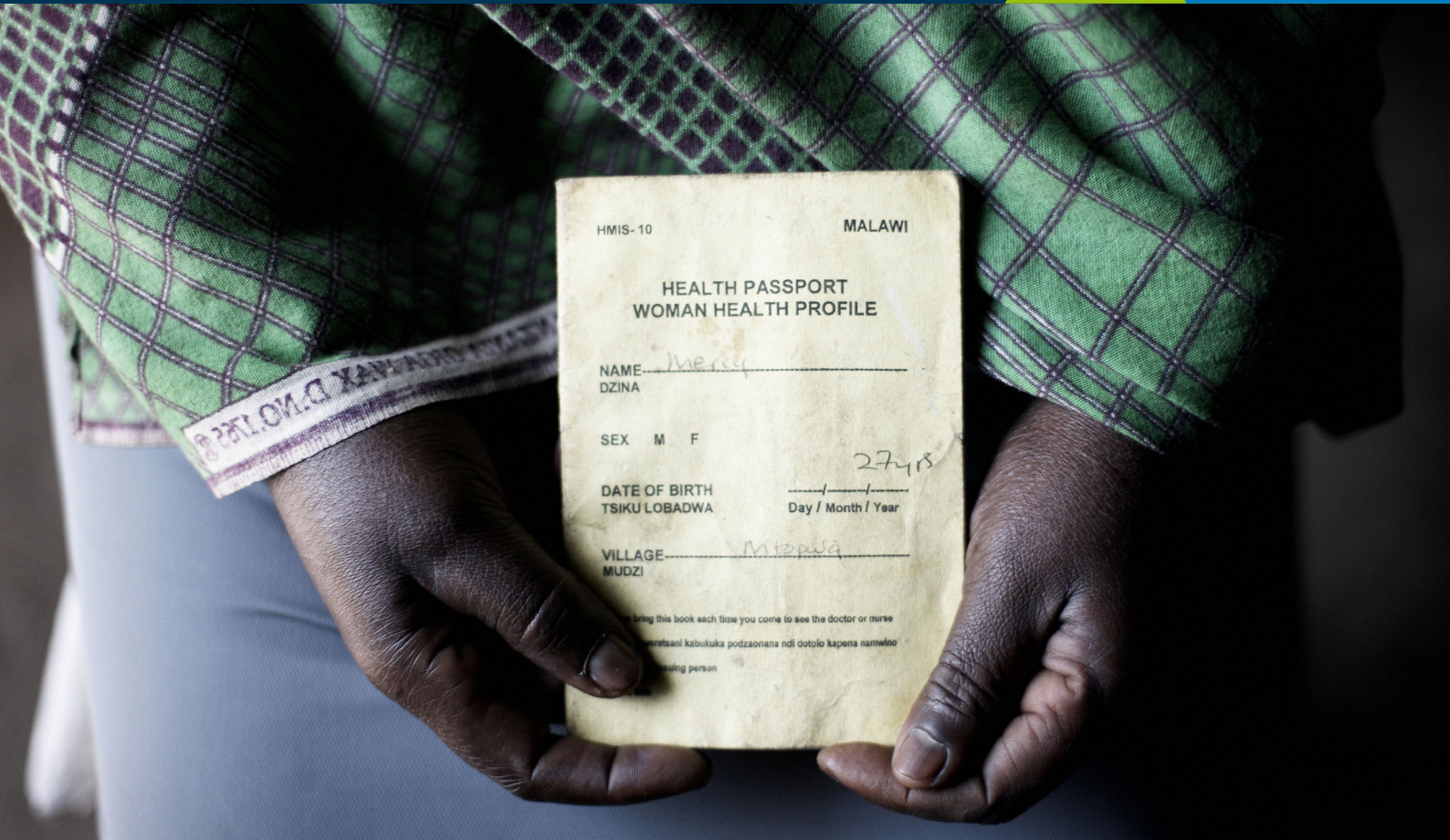
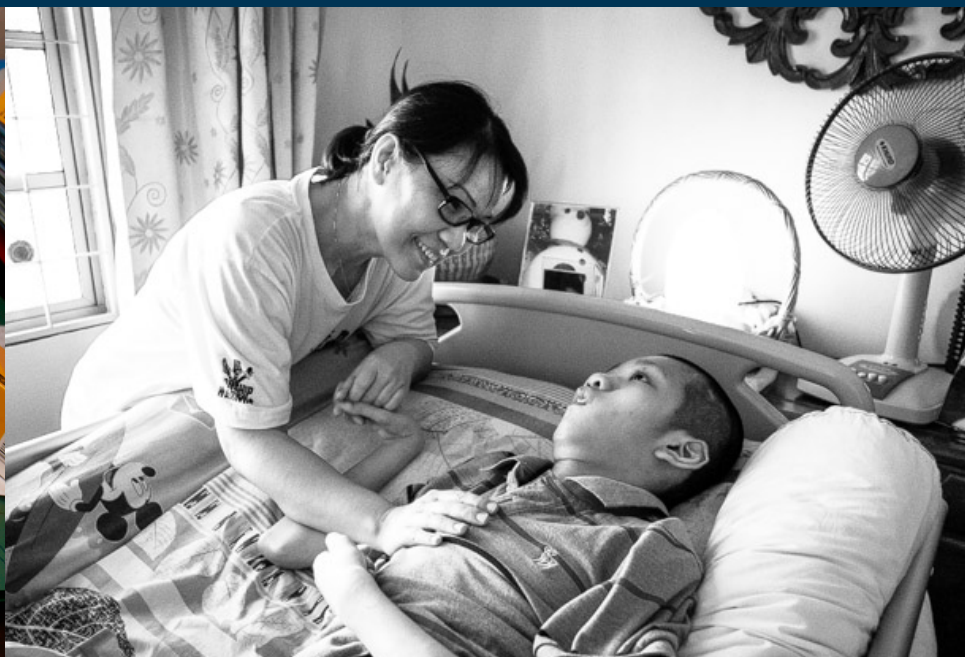
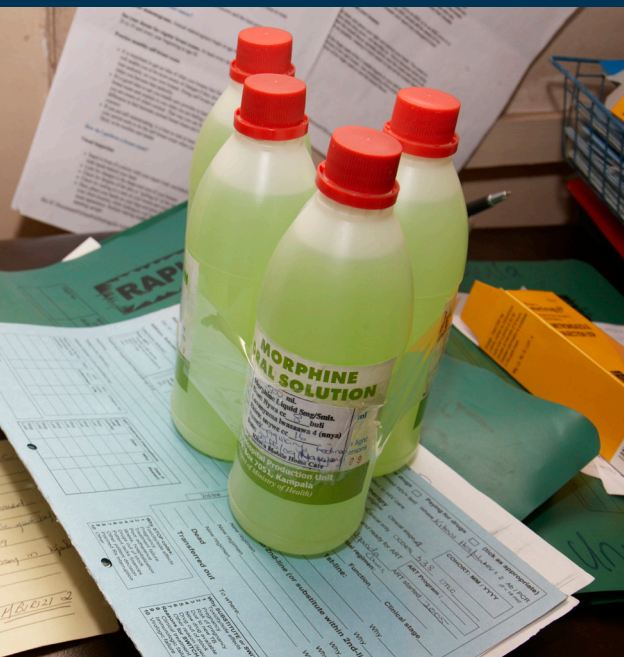


Palliative Care and the Global Goal for Health



Right. Smart. Overdue.



Acknowledgements

Special thanks to: Sharon Baxter, Sue Boucher, Sushma Bhatnagar, Joyce Chee, Stephen Connor, Liliana De Lima, Liz Gwyther, Hospice Foundation of Taiwan, Hospice Malaysia, Mhoira Leng, Aditya Manna, Joan Marston, Claire Morris, Christian Ntizimira, Katherine Pettus, M.R. Rajagopal, and Rini Vella.

Published in December 2015 by the Worldwide Hospice Palliative Care Alliance, London.

Copyright © 2015 Worldwide Hospice Palliative Care Alliance.

Author: Kate Jackson has asserted her right to be identified as the author of this work in accordance with the Copyright, Designs and Patents Act 1988.

All rights reserved. No part of this publication may be reproduced, stored in a retrieval system, or transmitted in any form or by any means, electronic, mechanical, photocopying, recording or otherwise, without the prior written permission of the publisher.

*Names in case studies have been changed throughout unless otherwise requested by the people involved.

Cover photo credits: Top, and bottom left: African Palliative Care Association, rights granted by the Diana, Princess of Wales Memorial Fund; bottom right, Hospis Malaysia.

Contents

Acknowledgements	
Introduction	1
What is the Global Goal for Health?	2
What is palliative care?	3
Palliative care as an essential part of the Global Goal for Health	4
Maternal and child health	5
Communicable diseases, specifically AIDS and tuberculosis	7
Non-communicable diseases	9
Substance dependence syndrome	11
Universal Health Coverage	13
Access to essential medicines	17
Health workforce	19
Challenges to strong focus on palliative care as part of the Global Goals	21
Palliative care: a vision for 2030	22
Recommendations	24
Conclusion	26
References	27

Introduction

This report has been produced by the International Association for Hospice and Palliative Care (IAHPC), the International Children’s Palliative Care Network (ICPCN), and the Worldwide Hospice Palliative Care Alliance (WHPCA) for global and national policy makers, development NGOs, funders, palliative care organisations and advocates. The aim of the report is to show how the Global Goal for Health and accompanying targets could support a focus on improving palliative care for people with life-threatening and life-limiting illness globally and to make recommendations for inclusion of palliative care within the Global Goal for Health.

Limited availability of and accessibility to palliative care globally for people living with life-threatening and life-limiting illness is a prominent example of extreme inequality and injustice. It is vital that governments and UN agencies include palliative care in the new Global Goals and create an environment that welcomes citizen advocacy. Citizens must empower themselves to work towards equitable access to palliative care as part of the Global Goal for Health.



*People occupy beds in corridors in Myanmar due to lack of capacity
Photo: Asia Pacific Hospice Palliative Care Network*

What is the Global Goal for Health?

The Global Goals were adopted by the leaders of 193 UN member states at the UN General Assembly in New York on 25 September 2015. The Global Goals build on the Millennium Development Goals set in 2000, and consist of 17 Goals plus their accompanying targets. These Goals aim to “build a better world by 2030”¹ by ending poverty, promoting prosperity and well-being for all, protecting the environment and addressing climate change.²

Palliative care is an essential component of the Global Goals, being a key part of Goal 3: ‘Good health & well-being: Ensure healthy lives and promote well-being for all at all ages’.

Global Goal 3 includes 13 targets. An inclusion of palliative care can contribute substantially to many of these. Particularly, palliative care is a key component of Universal Health Coverage as defined by the World Health Organization.³

The report will discuss how the global health goal and accompanying targets can support a focus on improving palliative care for people with life-threatening and life-limiting illness globally.

Targets of Global Goal 3 (those in **bold** are relevant to palliative care)

1. **By 2030, reduce the global maternal mortality ratio to less than 70 per 100,000 live births.**
2. **By 2030, end preventable deaths of newborns and children under 5 years of age, with all countries aiming to reduce neonatal mortality to at least as low as 12 per 1,000 live births and under-5 mortality to at least as low as 25 per 1,000 live births.**
3. **By 2030, end the epidemics of AIDS, tuberculosis, malaria and neglected tropical diseases and combat hepatitis, water-borne diseases and other communicable diseases.**
4. **By 2030, reduce by one third premature mortality from non-communicable diseases through prevention and treatment and promote mental health and well-being.**
5. **Strengthen the prevention and treatment of substance abuse, including narcotic drug abuse and harmful use of alcohol.**
6. By 2020, halve the number of global deaths and injuries from road traffic accidents.
7. By 2030, ensure universal access to sexual and reproductive health-care services, including for family planning, information and education, and the integration of reproductive health into national strategies and programmes.
8. **Achieve Universal Health Coverage, including financial risk protection, access to quality essential health-care services and access to safe, effective, quality and affordable essential medicines and vaccines for all.**
9. By 2030, substantially reduce the number of deaths and illnesses from hazardous chemicals and air, water and soil pollution and contamination.
10. Strengthen the implementation of the World Health Organization Framework Convention on Tobacco Control in all countries, as appropriate.
11. **Support the research and development of vaccines and medicines for the communicable and non-communicable diseases that primarily affect developing countries, provide access to affordable essential medicines and vaccines, in accordance with the Doha Declaration on the TRIPS Agreement and Public Health, which affirms the right of developing countries to use to the full the provisions in the Agreement on Trade Related Aspects of Intellectual Property Rights regarding flexibilities to protect public health, and, in particular, provide access to medicines for all.**
12. **Substantially increase health financing and the recruitment, development, training and retention of the health workforce in developing countries, especially in least developed countries and small island developing States.**
13. Strengthen the capacity of all countries, in particular developing countries, for early warning, risk reduction and management of national and global health risks.⁴

What is palliative care?



Photo: African Palliative Care Association, rights granted by The Diana, Princess of Wales Memorial Fund

The central focus of palliative care is to relieve suffering and to improve quality of life for adults and children affected by life-threatening and life-limiting illness. This includes their family members and carers.

Definition of palliative care

The World Health Organization (WHO) defines palliative care as: “an approach that improves the quality of life of patients and their families facing problems associated with life-threatening illness, through the prevention and relief of suffering, the early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”⁵ It is a holistic approach that aims to meet the needs of the whole person, not just to treat their clinical condition. It addresses the physical, social, psychological and spiritual issues facing people affected by life-threatening or life-limiting illness.

Palliative care should be provided in all settings, including in the community, rural hospitals and highly specialised centres in urban areas. The patient and the family are the focus of care, which should be provided by different

professionals in medicine, nursing, spiritual care, psychology, social work and any others as needed. A key aspect of palliative care is to support family members and carers, to improve their quality of life and well-being, an often neglected area of care.



Photo: Hospis Malaysia

Pain is one of the most common and distressing symptoms faced by people with life-threatening or life-limiting conditions. Strong opioids, which are under strict international control, are the most effective way to treat pain. Of these, oral morphine is the easiest and the cheapest in the international markets. However, morphine and other opioids are rarely available in many countries because of fears of diversion, misuse and dependence. These fears are the result of lack of awareness of policy makers and regulators and limited knowledge and skills of physicians, pharmacists and nurses on the adequate prescription and use of opioids. In most countries, this has resulted in laws and regulations that unduly restrict and limit access for patients with legitimate needs.

WHA resolution AG 67.19: Strengthening of Palliative Care as a Component of Comprehensive Care Throughout the Lifecourse⁶

WHO Member States unanimously accepted the resolution: Strengthening of Palliative Care as a Component of Comprehensive Care Throughout the Lifecourse during the 67th World Health Assembly in May 2014.

The resolution comprehensively details the responsibilities of the WHO, as well as Member States in strengthening palliative care as part of national health systems (see fig. 1).

The WHO Ad Hoc Technical Advisory Group on Palliative and Long-Term Care, an international group of leading palliative care experts, was formed to advise WHO on implementation of the resolution worldwide.

The Global Atlas of Palliative Care at the End of Life

In 2014, the World Health Organization and the Worldwide Hospice Palliative Care Alliance jointly published The Global Atlas of Palliative Care at the End of Life (Global Atlas).⁷ This publication quantified the need for and availability of palliative care worldwide, estimating that the number of people needing palliative care at the end of life was 20 million, while reporting that only 14% of that need was met. Research by the International Children's

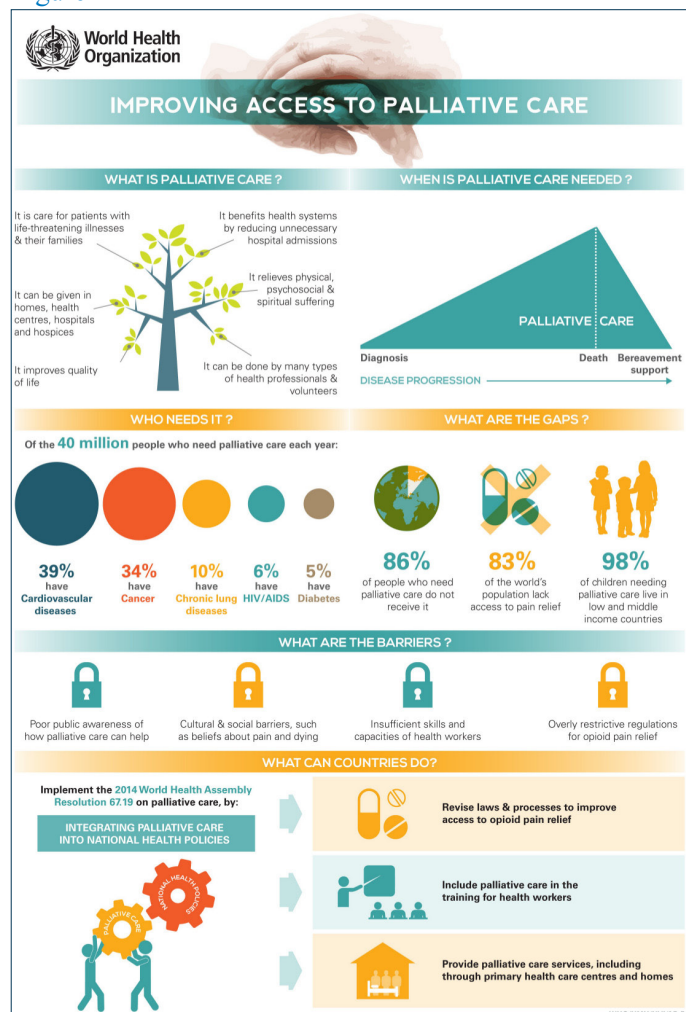
Palliative Care Network (ICPCN) identified that less than 1% of children are receiving palliative care.⁸

The Global Atlas identified people needing palliative care at the end of life. When including people needing palliative care early in the course of their illness the number doubles to at least 40 million each year. In addition there are several family members and carers for each affected person. Therefore the real need far exceeds the estimate published.

Palliative care as an essential part of the Global Goal for Health

Many of the Global Goal for Health targets cannot be met without a focus on palliative care. The sections below describe the role of palliative care in relation to each relevant target.

Figure 1



WHO Palliative Care infographic

Maternal and child health

By 2030, reduce the global maternal mortality ratio to less than 70 per 100,000 live births.

By 2030, end preventable deaths of newborns and children under 5 years of age, with all countries aiming to reduce neonatal mortality to at least as low as 12 per 1,000 live births and under-5 mortality to at least as low as 25 per 1,000 live births.

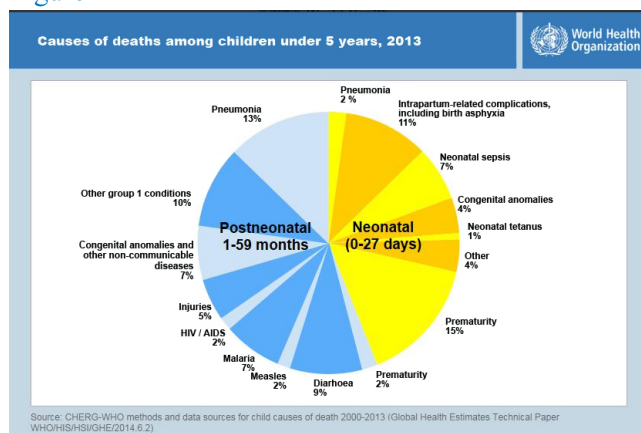


Joshua Hor and mom Calyn Hor, Hospis Malaysia

In 2015 5.9 million children under 5 years old died. Neonatal and peri-natal conditions accounted for 45% of these deaths (see fig. 2). WHO estimates that 98% of children needing palliative care live in Low- and Middle-Income Countries (LMICs), with almost 50% in Africa, which has only 3% of the world's health staff.⁹

Palliative care should be part of maternal, newborn and child health, to reduce the unnecessary and avoidable suffering of children. It should be integrated into care to strengthen the capacity of health systems at all levels, especially primary health care and community care.

Figure 2



WHO Causes of death among children under 5 years

Palliative care for children is based on good paediatric care which includes health promotion, prevention of infections and illnesses, immunisations, good nutrition, sanitation and management of the environment and customs that affect maternal and child health.

With improvements in living standards, and better paediatric care, more children are surviving preventable and curable conditions.

However, many children are born with a condition requiring palliative care.

The goal of children's palliative care is to promote the well-being of the child and help children live as long as possible, as well as possible, through reducing suffering and promoting quality of life. Well-being is promoted by enabling children to develop, play and experience childhood activities, while managing pain and symptoms.

Integration of children's and adults' palliative care into healthcare professionals' training in South Africa

The Department of Family Medicine in the University of the Free State has successfully integrated training in adult and children's palliative care into the undergraduate training of all health care professionals and into post-graduate qualifications. Working closely with the Departments of Paediatrics and Obstetrics, and a community children's hospice the Department of Family Medicine, ensures access to palliative care throughout the health system, in hospitals and primary health care clinics.

Communicable Diseases, specifically AIDS and tuberculosis (TB)

By 2030, end the epidemics of AIDS, tuberculosis, malaria and neglected tropical diseases and combat hepatitis, water-borne diseases and other communicable diseases.



Michael Mapanzi, Our Lady's Hospice, Zambia

Both adults and children need palliative care for HIV and AIDS. The Global Atlas estimates that over 1.2 million people with AIDS need palliative care at the end of life.¹⁰ Many more people living with HIV could benefit from palliative care from the point of diagnosis.

WHO recognises palliative care as an integral part of care for people living with HIV. It improves quality of life and can also support adherence to HIV treatment.

Worldwide 5.7% of adults needing palliative care at the end of life have HIV and AIDS. The burden is higher in the African region, where

this figure increases to around 42%. 10.23% of children needing palliative care at the end of life died from HIV and AIDS. In the African Region, those with HIV and AIDS represent 19% of children in need of palliative care.¹¹

Governments should review national health and HIV and TB disease strategies and policies to make sure that palliative care is part of these. It is vital to improve access to opioid pain medication and to develop palliative care guidelines and standards for HIV and TB.

Civil society groups have successfully campaigned for better access to treatment.¹² It is important for

governments to support their advocacy for a right to palliative care without fear of stigma or persecution.

Michael's story

My name is Michael. I am 15 years old and am from Zambia. In 2009 I developed a sore on my leg. Over time, the sore worsened and my leg became very swollen and itchy. I had to leave school and was taken to the hospital, where doctors discovered that I was HIV positive and that I had Kaposi's sarcoma – a type of skin cancer.

My priest took me to Our Lady's Hospice in Lusaka. The doctors told me that I can no longer be cured, but I am on second line antiretroviral treatments and am undergoing chemotherapy so that I can try to get better.

Before I came to the hospice, I got sick very often with malaria or the flu. Since I have been living at the hospice I have been feeling better. My nurse gives me medicine, washes and cleans my leg, and makes sure that I am feeling OK. I get morphine five times a day to help me deal with the pain in my leg.

Because of the palliative care, I do not have much pain anymore, and my problems are not as bad as they were before. My leg is no longer in very much pain.

I am glad that I live at the hospice where I have access to medicine, and people are around to look after me. My family gets to visit me every day, and they tell me that it is nice for them to see that I am no longer in much pain.

Non-Communicable Diseases

By 2030, reduce by one third premature mortality from non-communicable diseases through prevention and treatment and promote mental health and well-being.



A nurse in Malawi cares for a patient

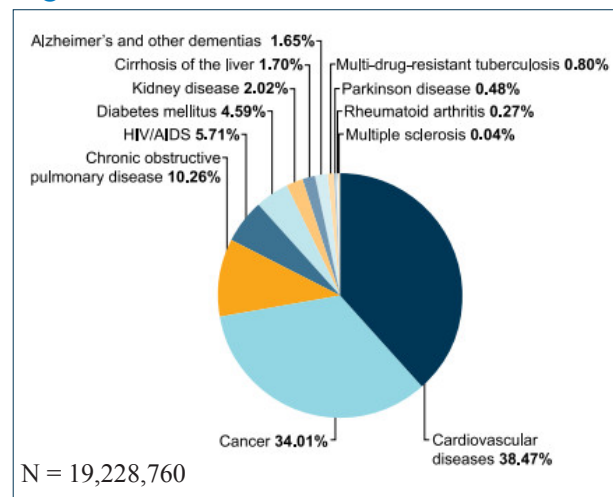
Photo: African Palliative Care Association, rights granted by The Diana, Princess of Wales Memorial Fund

At least 40 million people each year^{13,14} will need palliative care and of those over 93% suffer from NCDs (see fig. 3)¹⁵. The most common NCDs are cardiovascular diseases, cancers, chronic respiratory diseases and diabetes.

Almost three quarters of NCD deaths – 28 million – occur in LMICs. Barriers in access to essential pain relieving medications mean that millions of people with NCDs die in pain that should be both treatable and avoidable.

Treatment and management of NCDs is expensive and can be long term.¹⁶ Loss of

Figure 3



Distribution of adults in need of palliative care at the end of life by disease groups
Global Atlas of Palliative Care at the End of Life

income by the person with an NCD or their carer may exacerbate high healthcare costs. According to the WHO, the comprehensive care of NCDs encompasses primary prevention, early detection/screening, treatment, secondary prevention, rehabilitation and palliative care.^{17,18,19} Funding for the NCD response has been focussed on prevention and cure.²⁰ However, while mortality from NCDs may be prevented or delayed, these conditions will eventually require palliative care and most people with an NCD would benefit from accessing palliative care soon after diagnosis.

Mr Maji

Mr Maji lives in a small village in India. One day he starts to vomit blood. He loses about 10kgs of weight, has severe back pain and can't sleep, due to pain and worry. He and his wife sell their belongings and travel to Delhi. A series of 5am visits to the hospital reveal an advanced stage lung cancer which is beyond treatment.

The only thing that is treatable is pain. The doctors prescribe morphine and advise Mrs Maji to take her husband home. She begs the doctor to give her morphine for at least three months because she might not be able to return. That's not possible, due to legal barriers, so she quietly takes a one month reserve with her.

The couple who have sold their house to pay for access to health care return to their village where the man wants to die. One month later Mr Maji dies in pain because there is no money that can be spent on a dying body. It is more important to save it for those who are living.

This is not one unique story. This is happening to thousands of people country- and worldwide. People present to healthcare services too late for cure, and the least that can be done is that the pain and agony be relieved.

Substance dependence syndrome

Strengthen the prevention and treatment of substance abuse, including narcotic drug abuse and harmful use of alcohol.



Opioid medications are required for palliative care and dependence treatment

Photo: African Palliative Care Association, rights granted by The Diana, Princess of Wales Memorial Fund

The term ‘narcotic drug abuse’ is considered stigmatising and clinically inaccurate.^{21,22} To achieve healthy lives and well-being for all, basic palliative care for people suffering from serious illness, as well treatment for dependence syndrome (‘narcotic drug abuse’), must be integrated into public health systems worldwide.

Opioid pain medications such as morphine and methadone are required for palliative care and dependence treatment. Both are unavailable in more than three quarters of the LMICs.²³

Although the Single Convention on Narcotic Drugs notes that the use of opioid medications

is “indispensable for the relief of pain and suffering,” the paragraphs relating to control of these essential medicines no longer conform to the highest and most recent evidentiary standards.²⁵

The law, and its application in all UN member states, supports ‘opiophobia’^{26,27}, a term that denotes exaggerated concerns about the risks associated with opioids, preventing their appropriate medical use.²⁸ These concerns still dominate health, education, and drug control policy in many countries.

Well-trained professionals, sustainably funded

policies, and public health infrastructure that supports the treatment of pain and opioid dependence syndrome, can address this attitudinal barrier to accessing controlled medications.²⁹

Governments must integrate appropriate treatments for avoidable suffering, including stigma-free therapy for acute pain and dependence syndrome, into public health systems.

Universal Health Coverage

Achieve Universal Health Coverage, including financial risk protection, access to quality essential health-care services and access to safe, effective, quality and affordable essential medicines and vaccines for all.



Care planning in Malawi

Photo: African Palliative Care Association, rights granted by The Diana, Princess of Wales Memorial Fund

What is Universal Health Coverage?

Universal Health Coverage means that all people can use the promotive, preventive, curative, rehabilitative and palliative health services they need, of sufficient quality to be effective, while also ensuring that the use of these services does not expose the user to financial hardship.³⁰

It covers three key elements: access to quality essential health care services, access to safe, effective, quality and affordable essential medicines and vaccines; and protection from financial risk.

All populations, particularly the poorest and most marginalised, should be able to access the health care services that they require.

“I regard Universal Health Coverage as the single most powerful concept that public health has to offer.”

Margaret Chan,
WHO Executive Director

Universal Health Coverage is Right, Smart and Overdue ³¹

It's right. Health is a human right. No one should go bankrupt when they get sick. 17% of people in LMICs are pushed or pushed further into poverty by health spending.

It's smart. Universal Health Coverage reduces poverty and fuels economic growth. Universal Health Coverage lessens the impact of shocks on communities, from disease outbreaks to climate-related threats.

It's overdue. Health is the foundation of sustainable development and global resilience. The United Nations has unanimously endorsed Universal Health Coverage twice, but universal action has not yet been taken. Rich and poor countries have proven that Universal Health Coverage is possible.

Access to quality essential health care services and financial risk protection

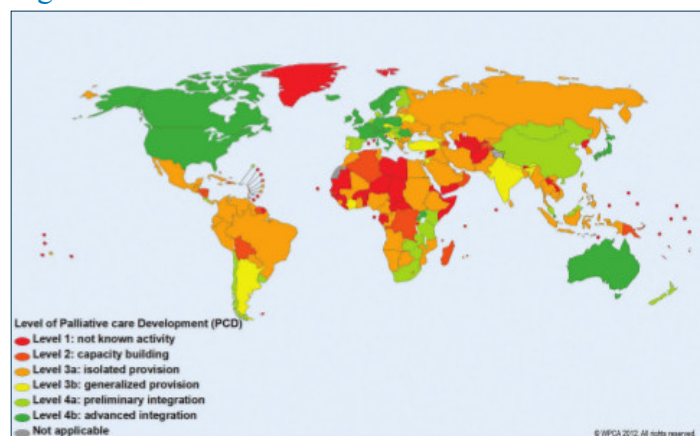
Palliative care is an essential health care service. People should be able to access it as soon as they are diagnosed with a life-threatening or life-limiting condition, and not just at the end of life. Criteria identifying people who would benefit from palliative care should be part of health guidelines.^{32,33}

Access to palliative care is difficult in many parts of the world. The Global Atlas reported that 42% of the world has no hospice and palliative care services and in an additional 32% of countries, palliative care services reached only a small percentage of the population (see fig. 4 and 5).

Palliative care is integrated in only 8.5% of country health systems so that 91.5% of health systems globally do not yet have integrated palliative care. LMICs have the greatest burden of disease, and also low availability of palliative care services and inadequate access to medications for pain treatment.

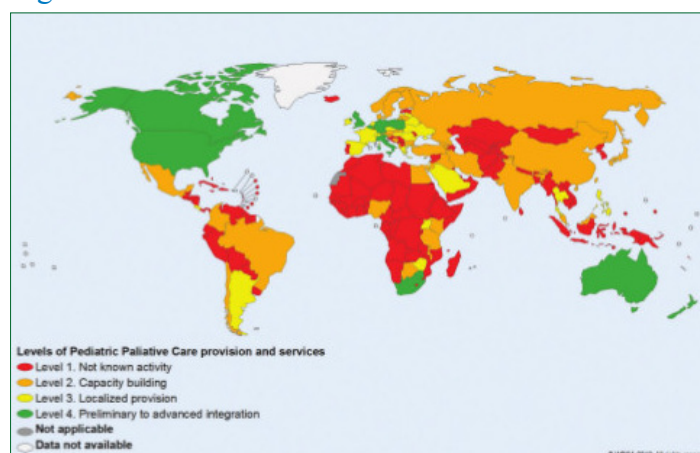
Barriers to accessing palliative care include: lack of government support for palliative care, low availability and accessibility of services and medications, poor education and training of staff, lack of evidence for and monitoring of palliative care, psychological and cultural barriers, and lack of political will.

Figure 4



Levels of palliative care development - all countries
Global Atlas of Palliative Care at the End of Life

Figure 5



Levels of paediatric palliative care development worldwide
Global Atlas of Palliative Care at the End of Life

Governments need to introduce laws that acknowledge palliative care as part of the healthcare system, draft national standards of care including palliative care, as well as clinical guidelines and protocols and a national strategy on palliative care implementation.

The indicator: “Access to palliative care assessed by morphine-equivalent consumption of strong opioid analgesics (excluding methadone) per death from cancer” is included in the WHO NCD Global Monitoring Framework.³⁴ However, since this indicator does not account for difference in access between poor and rich people within a country, it has not been included in the monitoring of Universal Health Coverage.

People should not face poverty or financial hardship because they need to access essential health care services. Financial risk occurs through paying for costly treatment not covered by national health insurance, loss of income by the person who is ill or their carers, or costly travel when treatment and care services are

situated far away from the family home.³⁵

In many parts of the world, hospice and palliative care services initiated by civil society or voluntary organisations, provide free services to the people and families accessing care.³⁶ Some countries include these services in health insurance schemes, although most do not.

Access to safe, effective, quality and affordable essential medicines and vaccines for all
Essential medicines, as defined by WHO, “satisfy the health care needs of the majority of the population; they should therefore be available at all times in adequate amounts and in appropriate dosage forms, at a price the community can afford.” The WHO model list of essential medicines is updated every two years and presents a list of minimum medicine needs for a basic healthcare system, listing the most efficacious, safe and cost-effective medicines for priority conditions.



Photo: African Palliative Care Association, rights granted by The Diana, Princess of Wales Memorial Fund

The WHO Model Lists for adults and for children include sections on medicines essential for pain and palliative care which list the medicines needed to treat the most common and distressing symptoms.³⁷ Unduly restrictive regulations are a barrier to accessing controlled medications.³⁸ This affects the provision of palliative care and the achievement of Universal Health Coverage. The issue of access to medications is discussed in detail in the following section.

Universal Health Coverage is Right in Costa Rica

Costa Rica has Universal Health Coverage, a national palliative care program, and a law that provides paid care-leave from work for the caregiver. Caregivers are entitled to take paid leave from work to care for a family member. Permissions are granted for 30 days and can be extended for up to six months.

Access to essential medicines

Support the research and development of vaccines and medicines for the communicable and non-communicable diseases that primarily affect developing countries, provide access to affordable essential medicines and vaccines, in accordance with the Doha Declaration on the TRIPS Agreement and Public Health, which affirms the right of developing countries to use to the full the provisions in the Agreement on Trade Related Aspects of Intellectual Property Rights regarding flexibilities to protect public health, and, in particular, provide access to medicines for all.



Working with controlled medicines in Uganda

Photo: African Palliative Care Association, rights granted by The Diana, Princess of Wales Memorial Fund

WHO estimates that only 60% of the need for essential medicines is met in the LMICs. For essential controlled medicines, this figure falls to less than 20%.^{39,40,41} Opiophobia, limited education on the use of opioids, high costs⁴², and restrictive laws and regulations account for medical professionals' reluctance to prescribe these medications for palliative care. Collaborations that involve community and local, national, regional, and transnational

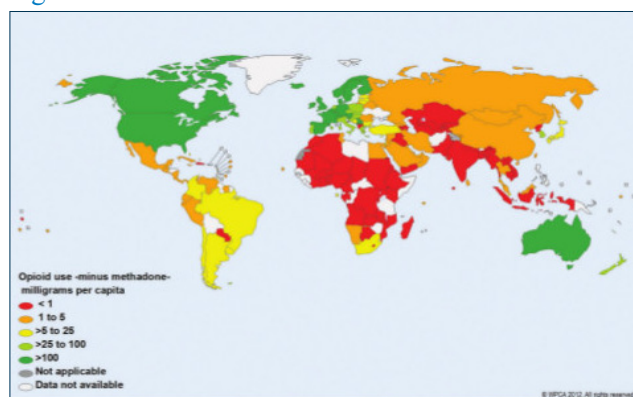
practitioners, can tackle these challenges developed in the shadow of the international drug control system.⁴³

Governments that report “low to inadequate consumption of medical opioids”^{44,45} must acknowledge that under-treatment of pain is a public health and human rights issue in their countries. Research is needed on best practice teaching and clinical models to improve

access to controlled medicines, the potential for development of national pharmaceutical industries, successful approaches to procurement and distribution,⁴⁷ barriers to access, and actual prevalence of diversion and abuse.^{48,49}

Staff must be trained to address opiophobia and improve confidence in working with opioid medications. This training must be intensive, long term and designed to change practice. Education must be based on proven models and practice. Lectures and symposia are not enough to change behaviour.⁵⁰

Figure 6



Morphine equivalent use worldwide
Global Atlas of Palliative care at the End of Life

The need for morphine in India

Screams rent the air as we entered the children's palliative care clinic in Kerala, India. A two year old child was writhing in pain, with violent muscle spasms. She was now out of intensive care where she had received artificial life support, but not pain relief.

Her father stood by, helplessness personified. He later confessed that he had thought about killing the whole family and committing suicide. Her mother had been behaving abnormally for weeks. Her 11 year old sister had left school. She had lost her childhood and had taken over the role of the mother. Morphine brought amazing relief to the girl. Not total; but enough for her to sleep. A week later, she had seizures. The child had had seizures earlier too; but this time, morphine became the culprit; it was stopped. It took a lot of persuasion by staff knowledgeable in the use of morphine to get the child back onto the medication and out of pain.

The child lived for a few months more at home, on morphine. Her father went back to work, though he had to leave work every two weeks to travel more than 100 kilometres to collect morphine. Her sister went back to school and her mother was helped by psychiatric treatment.

This kind of pain and suffering is not an exception; it is the rule for children and adults living in about 80% of the globe. A few scattered palliative care programmes do what they can; but the effect reaches too few, too late, and the results are fragmented.

They will continue to remain inadequate, destroying families, until restrictive drug policies are reformed and staff are trained to allow access to essential pain relieving medications and palliative care to be integrated into healthcare.

Health workforce

Substantially increase health financing and the recruitment, development, training and retention of the health workforce in developing countries, especially in least developed countries and small island developing States.



Training community health workers in Rwanda

Photo: Christian Ntizimira

Palliative care should be part of healthcare workforce training at all levels. Palliative care not only allows personnel to challenge and change values regarding the holistic care of patients and families with chronic life limiting illness, it improves the quality of health and social care systems.⁵¹ This includes mobilised communities driven by mutuality and compassion and civil society empowered to seek health care as a right.

The European Association for Palliative Care (EAPC) has outlined what core competencies health and social care professionals involved in palliative care should possess, in a consensus

“The palliative care training has made a huge impact. I now see the patient as a person and not a disease, I don’t avoid difficult conversations, I don’t order unnecessary investigations, I see them as part of a family, I do holistic care. It was not like that before. It feels more satisfying”

Internal medicine trainee following palliative care training.

White Paper.⁵² The WHA resolution suggests that palliative care be taught as part of basic, intermediate and specialist educational initiatives. Including palliative care in undergraduate training is important, and must include clinical modelling and holistic care seen in hospital and community settings.

Palliative care is recognised as a speciality in a small number of countries, including the UK, Canada, Australia, New Zealand, the USA and India. However, integration into postgraduate training programmes is often neglected, despite the fact that chronic disease management will be a daily reality for graduates. This tension can lead to harmful coping methods where medical staff avoid problems and patients.

“Then they make better cardiologists, better physicians.”

Senior physician advising integrating palliative care into medical training

Community health workers boost human resources for palliative care in Rwanda

Habimana was 10 years old when he came with his mom, Murekatete, to the palliative care department at the hospital in Rwanda. Both his eyes were out of their orbit due to a condition called exophthalmos, and the left eye was already blind. Because of his appearance, he was stigmatised by other children and his neighbours.

Habimana and his mother were referred to the palliative care team by a community health worker. The team provided palliative care and a referral to an ophthalmologist and an oncologist. Mrs Mukamana, a community health worker, had helped Habimana’s family plan his care so he could access healthcare and reduce the stigma due to his disease.

Community health workers added a referral role to their existing routine activities. This included being ‘doctor’s eyes’ on the patients and ‘support carer’s ears’ in the community. They identified neglected cases and assessed pain and other symptoms such as nausea or vomiting and reported these to the local Health Centre.

Each community health worker is well known and respected in their community and able to give the information and help that people need to access relevant care. Health providers, people accessing care, and their families agreed that a community health worker trained in palliative care reduces wasted time and unnecessary expenses.

To assure the sustainability of palliative care services, community health workers should be fully integrated into the public health system and trained to support patients and families.

Challenges to strong focus on palliative care as part of the Global Goals

Political will

Governments should respond to citizen demands for palliative care. These demands are rarely made though, due to lack of knowledge of palliative care and the absence of national champions – as people accessing palliative care are often too ill to advocate. Competing interests in the health professions and resistance to change are also significant factors impeding progress.

Funding

Government funding for palliative care services is mainly limited to high income countries. Most LMICs with fragile health systems have under-resourced public healthcare systems for the majority, and relatively good private systems charging out of pocket, or covered by insurance for the few. Palliative care providers must usually rely on foreign aid or local charitable contributions for funding.

Monitoring and measurement

Several attempts to develop global indicators to monitor palliative care as part of Universal Health Coverage have not succeeded. The Latin American Association for Palliative Care developed a set of ten indicators to monitor palliative care which have been implemented in the region.⁵³ Further testing on their usefulness and applicability in other regions is needed.

Evidence

Research evidence for palliative care is growing but still weak. Random controlled trials are limited because it is unethical to randomly assign people to palliative care.

Strength of civil society voice

There is limited national advocacy, citizen voice and demand for palliative care. A small number of professionalised civil society advocates are leading the movement. A global movement is needed to integrate palliative care into national healthcare systems.

International non-governmental organisations are becoming more active in promoting palliative care as demonstrated by passage of the WHA resolution on palliative care,⁵⁴ and its inclusion in the Global Goals. However, there is a lot more that needs to be done to empower people to lead the demand for palliative care.

Integration into health systems at primary health care (PHC)

Since the majority of patients needing palliative care can be cared for in PHC, and do not need specialist services, it is vital to integrate palliative care knowledge and skills into health professional education and provide basic training for PHC staff.

Education – basic, intermediate, specialist

The vast majority of health professionals globally still receive no education in palliative care as part of their professional training.⁵⁵ It is challenging to add palliative care modules to pharmacy, medical, nursing and social work curricula. Practicing professionals also need to include palliative care training to their continuing education. Few LMICs have the capacity to deliver training to qualify professionals as sub-specialists in palliative care, therefore educating community caregivers is essential.

Cost effective delivery of care

Evidence for the cost effectiveness of palliative care has centred on the importance of community home based care that results in reduction and prevention of unnecessary hospitalisation, diagnostics, emergency care and treatment.⁵⁶ Since the source of this evidence is high income countries, relevance to low and middle income country settings needs further research.

Palliative care: a vision for 2030

Ensuring healthy lives and promoting well-being for all at all ages by 2030 is an inspiring goal. Enabling people to live and die well must be a key part of addressing this. By 2030, there must be a major transformation. Citizens must be empowered to demand, drive and deliver palliative care for themselves and their communities.

A vision for 2030

All citizens globally will have embraced and driven the palliative care approach to ensure:

Equitable access

Everyone will access palliative care according to their needs, preferences and wishes and no-one will be left behind.

Inequities in care worldwide will be addressed. Care will be equitably available to and used by those with all conditions which can benefit from palliative care. National, regional and local borders and geographical differences will not represent different levels of access to palliative care.

Quality care

All citizens with life-limiting conditions worldwide, and their carers, will have as full and productive lives as possible through to the end of life, free from avoidable pain, distress and suffering.

Palliative care medications will be available and all healthcare staff will be trained in palliative care. Palliative care services will be accessible and used where people are and want to be, including homes, communities, care homes and hospitals. All carers and family members will be supported during the illness and bereavement.

Universal care

Universal Health Coverage, with palliative care as a fundamental component, will be available to all.

Everyone will access hospice and palliative



Chek Jamal and his wife, Hospis Malaysia

care when they need it, as part of Universal Health Coverage, without falling into financial hardship. The availability, accessibility and use of palliative care, and its financial implications, will be measured nationally and internationally and data will be available and accessible.

Innovation

The palliative care approach will lead the world in driving and scaling up innovative approaches, including internet-enabled technologies, to improve care and people's experiences and outcomes.

The world is changing rapidly with new models of care and new technologies. Innovation in palliative care will be critical to transforming services, improving care for people with life-limiting illness and placing more power and control into citizens' hands. The evidence base must be built alongside development.

Citizen-centred and citizen-driven care

Citizens will be actively engaged in demanding and driving care in their communities.

Everyone, including governments, communities, health providers and schools, will all participate in enabling citizens to demand, access and deliver the best possible care and support for themselves and each other when faced with illness, death and dying.



Photo: African Palliative Care Association, rights granted by The Diana, Princess of Wales Memorial Fund

Recommendations

Policy

1. Palliative care should be included within global and national policies and strategies relevant to the Global Goals, along with budget and resourcing to improve access and availability to meet the needs of all.
2. National strategies for diseases needing palliative care, and Universal Health Coverage strategies should be reviewed to ensure the inclusion of palliative care and pain relief.
3. Clinical palliative care guidelines and standards for all disease groups and major symptoms should be developed and adopted.

Advocacy

1. All people must be empowered to demand appropriate palliative care without fear of stigma or persecution.
2. People and organisations need to advocate for the inclusion of palliative care within strategies, policies, plans and monitoring frameworks relevant to the Global Goals at the global, regional and national level.
3. Palliative care must be democratised and driven by people's needs, wishes and preferences.

Service delivery

1. Governments and UN bodies should address inequities in care so that it is available to all.

Access to essential medications

1. Governments should address existing barriers to access to essential palliative care and pain medications available and accessible to all who need them.

Financing

1. Governments should undertake a thorough review of the inclusion of palliative care within health financing systems, including relevant health insurance and national healthcare schemes.

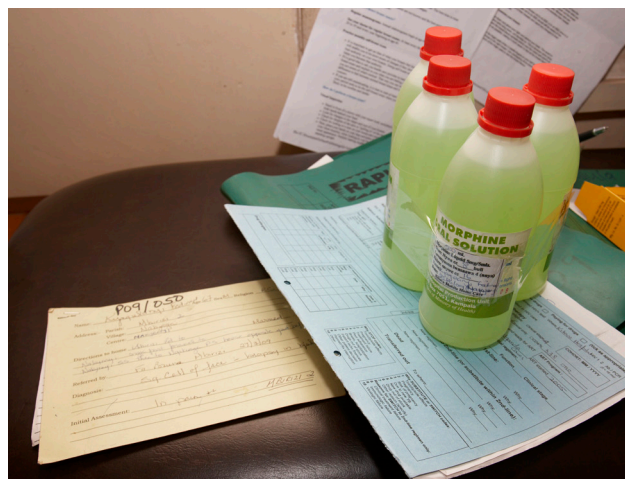


Photo: African Palliative Care Association, rights granted by The Diana, Princess of Wales Memorial Fund



Photo: Hospis Malaysia



Photo: Hospis Malaysia

Education

1. All healthcare staff should receive basic, intermediate and specialist palliative care training at the undergraduate and postgraduate level, and educational institutions and professional associations should support specialist certification.
2. People working with controlled medications should be trained in their procurement, prescription, and appropriate use. This training should be intensive, long term and designed to change practice.

Research

1. Governments should support research on adults and children's palliative care, particularly on integration of palliative care into primary health systems, cost-effectiveness of palliative care, and the financial burden that households face as a result of accessing, or not being able to access, hospice and palliative care services.

Monitoring

1. The Global Goals should include at least one global indicator on palliative care.
2. There should be national and international monitoring and measurement of the availability, accessibility and use of palliative care and controlled medications, and the financial implications of its use. This data should be openly available.



Bedside Teaching in Taiwan

Photo: Hospice Foundation of Taiwan

Conclusion

The Global Goals are a welcome vision for a future free from inequality, injustice, extreme poverty and climate disaster. Palliative care is an essential part of the Global Goal for Health, and can help achieve the targets involving maternal and child mortality, communicable and non-communicable diseases, ‘narcotic drug abuse’, Universal Health Coverage, access to essential medications, and strengthening of the health workforce.

Challenges to a strong focus on palliative care as part of the Global Goals include: a lack of political will and a global civic movement to promote it, funding challenges, lack of an indicator for monitoring palliative care, the need for integration into primary health systems, and workforce education gaps. However, progress

has been made, and the inclusion of palliative care in the Global Goals discussion, and in the World Health Assembly Resolution on palliative care presents the opportunity to work towards universal palliative care.

Global civil society, governments and UN agencies must insist that palliative care be included in the new Global Goals. Governments must create an environment that welcomes citizen advocacy. People must demand a voice in the local, national and global discussions and empower themselves to work towards equitable access to palliative care as part of the Global Goal for Health.



Photo: Hospice Ethiopia

References

1. Gov.uk, (2015). What are the Global Goals? [online] Available at: <https://www.gov.uk/government/news/what-are-the-global-goals>
2. United Nations Sustainable Development, (2015). United Nations 2015: Time for Global Action. [online] Available at: <http://www.un.org/sustainabledevelopment/>
3. World Health Organization. Health financing for universal coverage. [Online] Available at: www.who.int/health_financing/en
4. The Global Goals, (2015). Goal 3: Good Health & Well-Being. [online] Available at: <http://www.globalgoals.org/global-goals/good-health/>
5. World Health Organization, (2015). WHO Definition of Palliative Care. [online] Available at: <http://www.who.int/cancer/palliative/definition/en/>
6. World Health Assembly Resolution WHA67.19 Strengthening of palliative care as a component of comprehensive care throughout the life course. (24 May 2014). Available at: http://apps.who.int/gb/ebwha/pdf_files/WHA67/A67_R19-en.pdf
7. Connor, S. R., Sepulveda Bermedo, M. C. (eds.), (2014). Global atlas of palliative care at the end of life. World Health Organization & Worldwide Palliative Care Alliance. Available at: <http://www.who.int/nmh/GlobalAtlasofPalliativeCare.pdf>
8. International Children's Palliative Care Network & UNICEF, (2013). Assessment of the Need for Palliative Care for Children. Three Country Report: South Africa, Kenya and Zimbabwe. Available at: <http://www.icpcn.org/wp-content/uploads/2013/11/Assessment-of-the-Need-for-Palliative-Care-for-Children.-Three-Country-Report-South-Africa-Kenya-and-Zimbabwe.pdf>
9. World Health Organization, (2015). Maternal health. [online] Available at: http://www.who.int/maternal_child_adolescent/topics/maternal/en/
10. Connor, S. R., Sepulveda Bermedo, M. C. (eds.), (2014). Global atlas of palliative care at the end of life. World Health Organization & Worldwide Palliative Care Alliance. Available at: <http://www.who.int/nmh/GlobalAtlasofPalliativeCare.pdf>
11. Connor, S. R., Sepulveda Bermedo, M. C. (eds.), (2014). Global atlas of palliative care at the end of life. World Health Organization & Worldwide Palliative Care Alliance. Available at: <http://www.who.int/nmh/GlobalAtlasofPalliativeCare.pdf>
12. Treatment Action Campaign, (2015). About Us | TAC - Treatment Action Campaign. [online] Available at: http://www.tac.org.za/about_us
13. Estimate based on 20 million people needing palliative care at the end of life, as well as many more needing palliative care earlier in the course of their illness, and palliative care f Connor, S. R., Sepulveda Bermedo, M. C. (eds.), (2014). Global atlas of palliative care at the end of life. World Health Organization & Worldwide Palliative Care Alliance. Available at: <http://www.who.int/nmh/GlobalAtlasofPalliativeCare.pdf>
14. Connor, S. R., Sepulveda Bermedo, M. C. (eds.), (2014). Global atlas of palliative care at the end of life. World Health Organization & Worldwide Palliative Care Alliance. Available at: <http://www.who.int/nmh/GlobalAtlasofPalliativeCare.pdf>
15. Connor, S. R., Sepulveda Bermedo, M. C. (eds.), (2014). Global atlas of palliative care at the end of life. World Health Organization & Worldwide Palliative Care Alliance. Available at: <http://www.who.int/nmh/GlobalAtlasofPalliativeCare.pdf>
16. World Health Organization, WHO Global Coordination Mechanism on the Prevention and Control of NCDs <http://www.who.int/global-coordination-mechanism/en/>
17. World Health Organization, (2013). Global Action Plan for the Prevention and Control of NCDs 2013-2020. Available at: http://www.who.int/nmh/events/ncd_action_plan/en/
18. World Health Organization, (2015). WHO Global Coordination Mechanism on NCDs. NCDs, poverty and development. [online] Available at: <http://www.who.int/global->

coordination-mechanism/poverty-development/en/

19. World Health Organization, (2014) Non-communicable Diseases Global Monitoring Framework: Indicator Definitions and Specifications. Available at: http://www.who.int/nmh/ncd-tools/indicators/GMF_Indicator_Definitions_Version_NOV2014.pdf
20. Jackson, K., (2015). Palliative care advocates speak at WHO Dialogue on NCDs and development. ehospice. Available at: <http://www.ehospice.com/Default/tabid/10686/ArticleId/14873/>
21. Scholten W., (2015). Make your words support your message. *Journal of Pain & Palliative Care Pharmacotherapy*. 29. pp: 44–47.
22. World Health Organization, (2012). WHO Expert Committee on Drug Dependence, Thirty-fifth report. WHO Technical Report Series 973, Geneva. Available at <http://apps.who.int/iris/bitstream/10665/77747/1/WHOtrs973eng.pdf>
23. International Narcotics Control Board, (2015). Report of the International Narcotics Control Board on the availability of internationally controlled drugs: ensuring adequate access for medical and scientific purpose. New York.
24. United Nations, (1961). Single Convention on Narcotic Drugs, 1961. Available at https://www.incb.org/incb/en/narcotic-drugs/1961_Convention.html
25. Danenberg, E., Sorge, L.A., Wieniawski, W., Elliott, S., Amato, L. & Scholten, W.K. (2013). Modernizing methodology for the WHO assessment of substances for the international drug control conventions. *Drug and Alcohol Dependence*. 131(3). pp:175-81.
26. Bosnjak, S., Maurer, M.A., Ryan, K.M., Leon, M.X. & Madiye, G. (2011). Improving the availability and accesibility of opioids for the treatment of pain: The International Pain Policy Fellowship. *Journal of Supportive Care in Cancer*. 19. pp:1239-1247.
27. Krakauer, E., Phuong Cham, N., Husain, S., Hai Yen, N., Joranson, D., Khue, L. & Maurer, M., (2015) Toward Safe Accessibility of Opioid Pain Medicines in Vietnam and Other Developing Countries: A Balanced Policy Method. *Journal of Pain and Symptom Management*, 49(5).
28. Pain and Policy Studies Group. Glossary. Available at: <http://www.painpolicy.wisc.edu/glossary/opiophobia>
29. International Narcotics Control Board, (2010). Report of the International Narcotics Control Board on the Availability of Internationally Controlled Drugs: Ensuring Adequate Access for Medical and Scientific Purposes. Available at: https://www.incb.org/documents/Publications/AnnualReports/AR2010/Supplement-AR10_availability_English.pdf
30. World Health Organization, (2015). Health financing for universal coverage. [online] Available at: http://www.who.int/health_financing/en/
31. Universal Health Coverage Day Starter Toolkit, (2015). 1st ed. [ebook] Universal Health Coverage Day. Available at: <http://universalhealthcoverageday.org/starter-toolkit.pdf>
32. NHS Lothian, (2015). Supportive and Palliative Care Indicators Tool (SPICT). University of Edinburgh. Available at: <http://www.spict.org.uk/>
33. The Gold Standards Framework, (2011). The GSF Prognostic Indicator Guidance. Available at: <http://www.goldstandards-framework.org.uk/cd-content/uploads/files/General%20Files/Prognostic%20Indicator%20Guidance%20October%202011.pdf>
34. World Health Organization, (2014). NCD Global monitoring framework. Available at: http://www.who.int/nmh/ncd-tools/indicators/GMF_Indicator_Definitions_Version_NOV2014.pdf
35. Worldwide Hospice Palliative Care Alliance, (2014). Universal Health Coverage and Palliative Care. Do not leave those suffering behind. Available at: <http://www.thewhpc.org/resources/item/uhc-and-palliativecare>
36. Worldwide Hospice Palliative Care Alliance,

- (2014). Universal Health Coverage and Palliative Care. Do not leave those suffering behind. Available at: <http://www.thewhpc.org/resources/item/uhc-and-palliativecare>
37. World Health Organization, (2015). Model List of Essential Medicines. Available at <http://www.who.int/medicines/publications/essentialmedicines/en/>
 38. Vranken, M.J.M., Mantel-Teeuwisse, A.K., Jünger, S., Radbruch, L., Lisman, J., Scholten, W., Payne, S., Lynch, T., & Schutjens, M. D. B. (2014). Legal Barriers in Accessing Opioid Medicines: Results of the ATOME Quick Scan of National Legislation of Eastern European Countries. *Journal of Pain and Symptom Management*. 48(6). pp: 1135 – 1144
 39. Bazargani, Y.T., Ewen, M., de Boer, A., Leufkens, H.G.M., Mantel-Teeuwisse, A.K., (2014). Essential medicines are more available than other medicines around the globe. *PLoS ONE* 9(2)
 40. United Nations, (2008). Access to affordable essential medicines in Delivering on the Global Partnership for Achieving the Millennium Development Goals: MDG Gap Task Force Report 2008.
 41. Connor, S. R., Sepulveda Bermedo, M. C. (eds.), (2014). Global atlas of palliative care at the end of life. World Health Organization & Worldwide Palliative Care Alliance. Available at: http://www.who.int/nmh/Global_Atlas_of_Palliative_Care.pdf
 42. De Lima, L., Pastrana, T., Radbruch, L. & Wenk, R., (2014). Cross-Sectional Pilot Study to Monitor the Availability, Dispensed Prices and Affordability of Opioids Around the Globe. *Journal of Pain and Symptom Management*. 48(4)
 43. Burris, S., & Davis, C.S., (2009). A Blueprint for Reforming Access to Opioid Medications: Entry Points for International Action to Remove the Policy Barriers to Care and Treatment. Social Science Research Network. Available at: http://papers.ssrn.com/sol3/papers.cfm?abstract_id=1356815
 44. International Narcotics Control Board, (2010). Report of the International Narcotics Control Board on the Availability of Internationally Controlled Drugs: Ensuring Adequate Access for Medical and Scientific Purposes. Available at: https://www.incb.org/documents/Publications/AnnualReports/AR2010/Supplement-AR10_availability_English.pdf
 45. World Health Organization, (2012). World Health Organization Briefing Note — April 2012. Access to Controlled Medications Programme Component: Developing WHO Clinical Guidelines on Pain Treatment. Available at: http://www.who.int/medicines/areas/quality_safety/ACMP_BrNote_PainGLs_EN_Apr2012.pdf
 46. Human Rights Council. (2015). Study on the impact of the world drug problem on the enjoyment of human rights. Report of the United Nations High Commissioner for Human Rights. Available at: <https://dl.dropboxusercontent.com/u/64663568/library/Study-impact-of-the-world-drug-problem-on-human-rights.pdf>
 47. Krakauer, E.L., Nguyen, T.P., Husain, S.A., Nguyen, T.H., Joranson, D.E., Luong, N.K., & Maurer, M.A. (2015). Toward safe accessibility of opioid pain medicines in Vietnam and other developing countries: a balanced policy method. *Journal of Pain and Symptom Management*. 49(5). pp: 916-922
 48. Pallium India, International Association for Hospice And Palliative Care, & Pain Policy Studies Group. (2012). A Morphine Manifesto. *Journal of Pain and Palliative Care Pharmacotherapy*. 26(2). pp: 144-145
 49. Payne, S., Leget, C., Peruselli, C., & Radbruch L. (2012). Quality indicators for palliative care: debates and dilemmas. *Palliative Medicine*. 26(5). Pp: 679-680
 50. Yang, H.B., Nelesen, R.A., Montross, L.P., Whitmore, S.M., & Ferris, F.D., (2013). Comparison of international medical graduates with US medical students and residents after a four-week course in palliative medicine: a pilot study. *Palliative Medicine*. 16(5). pp: 471-477.
 51. Leng, M., (2011). Networking and training in palliative care – Challenging values and changing practice. *Indian Journal of Palliative Care Supplement* Jan 2011. Available at: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3140095/>
 52. European Association for Palliative Care, (2013). Core competencies in palliative care:

an EAPC White Paper on palliative care education – part 1. *European Journal of Palliative Care*. 20(2). Available at: <http://www.eapcnet.eu/LinkClick.aspx?fileticket=xc-tl28Ttfk%3D&tabid=194>

53. Pastrana, T., Torres-Vigil, I. & De Lima, L., (2014). Palliative care development in Latin America: An analysis using macro indicators. *Palliative Medicine*
54. World Health Assembly, (2014). Resolution WHA67-19 Strengthening of palliative care as a component of comprehensive care throughout the life course. Available at: http://apps.who.int/gb/ebwha/pdf_files/WHA67/A67_R19-en.pdf?ua=1
55. Sullivan, A.M., Lakoma, M.D. & Block, S.D. (2003). The Status of Medical Education in End-of-life Care: A National Report. *Journal of General Internal Medicine*. 18 (9), pp: 685–695. Available at: <http://onlinelibrary.wiley.com/doi/10.1046/j.1525-1497.2003.21215.x/full>
56. Smith, S., Brick, A., O'Hara, S., & Normand, C., (2014). Evidence on the cost and cost effectiveness of palliative care: A literature review. *Palliative Medicine*. 28(2). pp:130-150.

About the Worldwide Hospice Palliative Care Alliance

The Worldwide Hospice Palliative Care Alliance (WHPCA) is an international non-governmental organisation focusing exclusively on hospice and palliative care development worldwide. We are a network of national and regional hospice and palliative care organisations and affiliate organisations. We believe that no-one with a life-limiting condition should live and die with unnecessary pain and distress. Our vision is a world with universal access to hospice and palliative care. Our mission is to foster, promote and influence the delivery of affordable, quality palliative care.

www.thewhpca.org

About the International Association for Hospice & Palliative Care

The International Association for Hospice and Palliative Care is a membership organisation dedicated to the promotion and development of palliative care. Our Vision is for universal access to palliative care, integrated in a continuum of care with disease prevention and treatment. Our Mission is to improve the quality of life of adults and children with life-threatening conditions and their families. We work with governments, agencies and individuals, to improve knowledge and foster opportunities in education, research and training around the globe.

www.hospicecare.com

About the International Children's Palliative Care Network

The International Children's Palliative Care Network (ICPCN) is a network of individuals and organisations working within the field of hospice and palliative care for children and the only global information hub relevant specifically to children's palliative care. Our Vision is a world where children's palliative care is acknowledged and respected as a unique service, and every infant, child and young person with life-limiting or life-threatening conditions and their families can receive the best quality of life and care regardless of which country they live in. Our activities include awareness raising, lobbying for the development of children's palliative care services and the sharing of expertise, skills and knowledge.

www.icpcn.org