

# Integrating palliative care and symptom relief into primary health care

A WHO guide for planners, implementers and managers



World Health  
Organization

Integrating palliative care and symptom relief into primary health care: a WHO guide for planners, implementers and managers

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# Contents

<b>Foreword</b>	v
<b>Acknowledgements</b>	vi
<b>Abbreviations and acronyms</b>	vii
<b>Introduction</b>	1
<b>Chapter 1. What is palliative care?</b>	5
<b>Chapter 2. Access to palliative care</b>	9
<b>Chapter 3. What is primary care and why should palliative care be integrated into it?</b>	13
<b>Chapter 4. Essential Package of Palliative Care for Primary Health Care</b>	19
<b>Chapter 5. Implementing palliative care in primary care</b>	29
<b>Chapter 6. Ensuring access to essential controlled medicines</b>	41
<b>Chapter 7. Integration of palliative care strengthens public health systems and promotes UHC</b>	45
<b>Chapter 8. Need for research and quality improvement</b>	49
<b>References</b>	53
<b>Annex 1</b>	
Declaration of Alma-Ata (1978)	61
<b>Annex 2</b>	
Sixty-second World Health Assembly resolution WHA62.12 on Primary health care, including health system strengthening	63
<b>Annex 3</b>	
Sixty-ninth World Health Assembly resolution WHA69.24 on Strengthening integrated, people-centred health services	65
<b>Annex 4</b>	
Sixty-seventh World Health Assembly resolution WHA67.19 on Strengthening of palliative care as a component of comprehensive care throughout the life course	67
<b>Annex 5</b>	
Sample curricula in palliative care for primary health care providers	71
<b>Annex 6</b>	
Links	76
<b>Annex 7</b>	
Glossary	78



# Foreword

The World Health Assembly has resolved that palliative care is “an ethical responsibility of health systems” and that integration of palliative care into public health care systems is essential for the achievement of the Sustainable Development Goal on universal health coverage (WHA 67.19). Yet palliative care and symptom relief are rarely accessible in a number of countries. As a result, suffering on a massive scale remains unrelieved, and progress toward universal health coverage is at risk. The World Health Assembly also has called for Member States to “put people at the centre of health care” by providing “comprehensive primary care services, including health promotion, disease prevention, curative care and palliative care, that are integrated with other levels of care” (WHA 62.12).

The great majority of people who need palliative care prefer to remain at home, thus, it is medically and ethically necessary that palliative care be provided in the community, as part of primary health care. It is neither possible nor necessary that palliative care specialists provide most palliative care and symptom relief. Primary health care providers with basic training in palliative care and symptom relief can respond effectively to most palliative care needs and arrange for transfer to a higher level of care when necessary. Emphasis should be given to continuity of care, respect for patients’ values, equitable access to services, and attention not only to patients but also to their families.

This manual is part of a series of WHO publications on palliative care. Their objective is not to provide clinical guidelines, but rather practical guidance on integrating palliative care and symptom relief into health care systems. It is intended, to assist anyone involved with planning, implementing, managing or assuring the quality of PHC to integrate palliative care and symptom control. With this guide, WHO reiterates its commitment to answering the needs and expectations of all people, especially the most vulnerable.



Dr Naoko Yamamoto  
Assistant Director-General  
Universal Health Coverage and Health Systems  
World Health Organization  
Geneva  
Switzerland

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# Abbreviations and acronyms

<b>AIDS</b>	acquired immune deficiency syndrome
<b>APCA</b>	African Palliative Care Association
<b>CHC</b>	community health centre
<b>CHW</b>	community health worker
<b>EAPC</b>	European Association of Palliative Care
<b>EP PHC</b>	Essential Package of Palliative Care for Primary Health Care
<b>HIC</b>	high-income country
<b>HIV</b>	human immunodeficiency virus
<b>IAHPC</b>	International Association for Hospice and Palliative Care
<b>INCB</b>	International Narcotics Control Board
<b>LMICs</b>	low- and middle-income countries
<b>NCD</b>	noncommunicable disease
<b>NGO</b>	nongovernmental organization
<b>PHC</b>	primary health care
<b>SSRI</b>	selective serotonin reuptake inhibitor
<b>UHC</b>	universal health coverage
<b>UN</b>	United Nations
<b>UNICEF</b>	United Nations Children's Fund
<b>WHA</b>	World Health Assembly
<b>WHO</b>	World Health Organization





# Introduction

Inequality of access to palliative care and symptom relief is one of the greatest disparities in global health care (1). Currently, there is avoidable suffering on a massive scale due to lack of access to palliative care and symptom relief in low- and middle-income countries (LMICs) (1). Yet basic palliative care that can prevent or relieve most suffering due to serious or life-threatening health conditions can be taught easily to generalist clinicians, can be provided in the community and requires only simple, inexpensive medicines and equipment. For these reasons, the World Health Assembly (WHA) resolved that palliative care is “an ethical responsibility of health systems” (2). Further, most patients who need palliative care are at home and prefer to remain there. Thus, it is imperative that palliative care be provided in the community as part of primary care (Annex 1). This document was written to assist ministries of health and health care planners, implementers and managers to integrate palliative care and symptom control into primary health care (PHC).

This second in a series of World Health Organization (WHO) guides on palliative care follows a general one entitled *Planning and implementing palliative care services: a guide for programme managers*, published in 2016 (3). The current document may be used by itself for integrating palliative care into primary care or in combination with the earlier guide by those working to integrate palliative care into multiple levels of a health care system.

This document is not a clinical manual, and does not provide clinical guidelines. Rather, it contains detailed information about what palliative care is and should be, the rationale for it being a medical and moral imperative, an Essential Package of Palliative Care for Primary Health Care (EP PHC) and a method for implementing palliative care within primary care in a way that strengthens health care systems (Annex 2). It represents the collective knowledge, experience and recommendations of a group of experienced palliative care clinicians, all of whom either are also primary care clinicians or work in LMICs, or both.







## 1

# What is palliative care?

WHO defines palliative care as the prevention and relief of suffering of adult and paediatric patients and their families facing the problems associated with life-threatening illness (4). These problems include physical, psychological, social and spiritual suffering of patients and psychological, social and spiritual suffering of family members. Palliative care (5):

- entails early identification and impeccable assessment and treatment of these problems;
- enhances quality of life, promotes dignity and comfort, and may also positively influence the course of illness;
- provides accompaniment for the patient and family throughout the course of illness;
- should be integrated with and complement prevention, early diagnosis and treatment of serious or life-limiting health problems;
- is applicable early in the course of illness in conjunction with other therapies that are intended to prolong life;
- provides an alternative to disease-modifying and life-sustaining treatment of questionable value near the end of life and assists with decision-making about optimum use of life-sustaining treatment;
- is applicable to those living with long-term physical, psychological, social or spiritual sequelae of serious or life-threatening illnesses or of their treatment;
- accompanies and supports bereaved family members after the patient's death, if needed;
- seeks to mitigate the pathogenic effects of poverty on patients and families and to protect them from suffering financial hardship due to illness or disability;
- does not intentionally hasten death, but provides whatever treatment is necessary to achieve an adequate level of comfort for the patient in the context of the patient's values;
- should be applied by health care workers at all levels of health care systems, including primary care providers, generalists and specialists in many disciplines and with various levels of palliative care training and skill, from basic to intermediate to specialist;
- encourages active involvement by communities and community members;
- should be accessible at all levels of health care systems and in patients' homes; and
- improves continuity of care and thus strengthens health systems.

The specific types and severity of suffering vary by geopolitical situation, socioeconomic conditions and culture. People in LMICs often endure less healthy social conditions. They also typically have less access to disease prevention, diagnosis and treatment, to social support, and to specialists and specialized services of many kinds than people in high-income countries (HICs). For example, many people around the world have limited or no access to cancer chemotherapy, radiation therapy or surgery, to effective chemotherapy for multidrug resistant tuberculosis, or to neonatal intensive care. Palliative care should never be considered a substitute for disease prevention and treatment or critical care, and palliative care workers have a responsibility to advocate for these interventions wherever they are not yet accessible (5). But palliative care should also be universally accessible (2).

Many countries also lack rehabilitation medicine specialists and services and long-term care facilities to care for people with non-life-threatening but serious disabilities such as paraplegia or quadriplegia or those due to brain injuries or congenital anomalies. In addition, mental health services and social welfare programmes may be of limited capacity, difficult to access or unavailable. Palliative care can help to fill these needs (Table 1). Further, the types of suffering typically associated with life-threatening illness – pain, other physical symptoms, psychological symptoms – also occur acutely or in association with non-life-threatening conditions. But in low-resource settings, prevention and relief of acute or non-life-threatening suffering typically are inadequate or unavailable. In countries where pain medicine does not yet exist as a specialty and where prevention and relief of pain from trauma or burns or surgery are inadequate, clinicians trained in palliative care can fill this therapeutic void. In these settings, clinicians trained in palliative care can intervene either by training colleagues in symptom control, by providing direct symptom relief, or both. Planning and implementing palliative care services should be based on assessment of the types and extent of inadequately prevented or relieved physical, psychological, social or spiritual suffering. This attention to local needs is necessary for palliative care services to be people-centred: tailored to local need and to the needs of individual patients and families (Annex 3) (1,6).









## 2 Access to palliative care

In 2014, the Sixty-seventh World Health Assembly resolved that “it is the ethical duty of health care professionals to alleviate pain and suffering, whether physical, psychosocial or spiritual, irrespective of whether the disease or condition can be cured ... ” (Annex 4) (2). The same resolution states that “palliative care is an ethical responsibility of health systems ... ” and that integration of palliative care into public health care systems is essential for achievement of Sustainable Development Goal 3.8: universal health coverage (UHC). Thus, palliative care is not an option but a medical and ethical necessity that should be accessible by anyone in need at all levels of health care systems.

Despite compelling evidence of a huge burden of remediable suffering and of the effectiveness of palliative care to relieve suffering, palliative care is poorly accessible in some HICs and is rarely accessible in LMICs (7). Data from the International Narcotics Control Board (INCB) show that 91% of the morphine consumed worldwide in 2013 was consumed in HICs, which have only 19% of the world’s population. People in LMICs, which account for 81% of the world’s population, only consumed 9% (8). Given that morphine is essential to relieve moderate and severe pain and that morphine consumption is the most common – although imperfect – measure of access to palliative care, the data reveal an enormous disparity between rich and poor in access to relief, both of pain in particular and of suffering in general (9,10). Available data indicate that 74% of countries – virtually all of them LMICs – had at best isolated palliative care provision as of 2013 (11).

A variety of barriers have impeded development and accessibility of palliative care services. There have been misunderstandings about the definition of palliative care. Most notably, sometimes it is not understood (1):

- that palliative care is not only for the dying but for any patient suffering in association with serious or life-threatening health problems;
- that palliative care is not an alternative to disease prevention and treatment but should be integrated with them;
- that palliative care not only relieves suffering, but also anticipates and prevents it;
- that there is a massive burden of unnecessary suffering due to pain, other physical symptoms, and psychological, social and spiritual distress; and
- that palliative care is essential to achieve UHC.

Additional barriers include:

- lack of a national palliative care policy, a national palliative care strategic plan, and national palliative care clinical guidelines in many countries;
- lack of basic, intermediate and specialist training programmes in palliative care;
- lack of inpatient and outpatient staff positions that include palliative care as an official responsibility and that enable trained clinicians to be paid for practicing palliative care;
- lack of insurance coverage of palliative home care;
- excessive fear of opioid side effects, addiction and diversion, resulting in excessively restrictive opioid prescribing regulations; and
- lack of financial incentive for importation or local production of oral and injectable morphine.

Throughout the world, but especially in LMICs, most people, when given the choice, wish to die at home, and most people in need of palliative care are at home. Therefore, it is essential that palliative care be accessible in the community and in patients' homes. This requires integration of palliative care into PHC in keeping with the WHO Framework on integrated, people-centred health services, adopted by the Seventy-ninth World Health Assembly in 2016 (6). The Framework calls for a reorientation of health care to prioritize primary and community care services and coordinated and continuous care – including palliative care – over time, for people with complex health problems. It is neither feasible nor necessary for most palliative care to be provided by palliative care specialist physicians. Rather, most palliative care can and should be provided by primary care practitioners with at least basic training in palliative care of at least 35 hours (Annex 5). These practitioners may include general practitioners, family physicians, clinical officers, assistant doctors, nurse-practitioners, feldsher, nurses, social workers and trained and supervised lay counsellors based at community health centres (CHCs). Community health workers (CHWs) can provide frequent emotional support for the patient and family and report to a clinician at CHCs.





## 3

## What is primary care and why should palliative care be integrated into it?

According to the WHO Constitution: "Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity. The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being" (12). Further, "health is a fundamental human right indispensable for the exercise of other human rights" (13). Around the world, especially in LMICs, most people with any of the myriad types of suffering associated with serious or life-threatening health problems lack access to palliative care. It is estimated that 40 million terminally ill people, and millions of others not imminently dying, need palliative care every year. But 86% of those in need do not receive it, including 98% of children in need in LMICs (1, 11). Access is least likely in the community where most of the patients are and wish to remain. Thus, millions of vulnerable people are being denied their right to the highest attainable standard of well-being. Most suffering due to serious or life-threatening health problems can be relieved with inexpensive, safe and effective medicines and equipment prescribed by any physician, clinical officer or assistant doctor with basic palliative care training. Typically, the only care available in the community is PHC. Given these facts, it is both medically and morally imperative that palliative care be integrated into PHC (14, 15).

What is primary care?

### According to the Declaration of Alma-Ata from 1978, PHC (Annex 1):

- is essential health care based on practical, scientifically sound and socially acceptable methods and technology;
- should be universally accessible to individuals and families in the community;
- should be affordable for the community and country at every stage of their development;
- is the central function and main focus of the country's health system;
- is essential for the overall social and economic development of the community; and
- is the first level of contact with the national health system and brings health care as close as possible to where people live and work.

### In keeping with the Declaration of Alma-Ata, PHC also (Annex 2):

- should address the main health problems in the community;
- should provide health-promotive, preventive, curative, rehabilitative and palliative services across the life-course;
- should include:
  - education on prevailing health problems and on preventing and controlling them;
  - promotion of good nutrition, safe water and basic sanitation;
  - maternal and child health care, including family planning;
  - immunization against the major infectious diseases;

- appropriate treatment for common diseases and injuries, including continuity of care for people with chronic conditions;
- basic palliative care; and
- provision of essential medicines, including essential controlled medicines such as oral and injectable morphine;
- should be integrated into a referral system and information system resulting in comprehensive, coordinated and continuous health care for all;
- should give priority to those most in need; and
- should be provided by an appropriately trained team that includes physicians and nurses and also may include clinical officers, assistant doctors, feldshers, nurses, midwives, community workers as applicable, as well as traditional practitioners, as appropriate, to respond to the expressed health needs of the community.

## Overlapping principles of PHC and palliative care

The inseparability of PHC and palliative care is evident both from the Declaration of Alma-Ata (Annex 1) and from more recent international documents on PHC (16, 17, 18). World Health Assembly resolution WHA62.12 in 2009 reaffirmed the principles of PHC, including equity, solidarity, social justice, universal access to services, multisectoral action, decentralization and community participation as the basis for strengthening health systems (Annex 2). All are also principles of palliative care. This resolution also emphasized putting people at the centre of health care by adopting delivery models focused on the local and district levels that provide comprehensive PHC services. These include health promotion, disease prevention, curative care and palliative care that are integrated with other levels of care and coordinated according to need, while assuring effective referral to secondary and tertiary care. PHC, like palliative care, benefits from participation of civil society and the community in policy formulation and accountability mechanisms to ensure that the health system is socially acceptable, universally accessible and affordable, and scientifically sound (19). In addition, PHC and palliative care have in common an emphasis on continuity of care and solidarity (accompaniment), respect for patients' values and attention not only to patients, but also to their families (7, 20, 21).

### Box 1. Core values for PHC include:

- **equity**
- **social justice**
- **universality**
- **people-centredness**
- **community protection**
- **participation**
- **scientific soundness**
- **personal responsibility**
- **self-determination**
- **self-reliance**

Source: Adapted from WHO Regional Office for the Western Pacific (2010) (20).

## Overcoming fragmentation in health care services through integration

According to the first global monitoring report on UHC, at least 400 million people lack access to one or more essential health services (22). This is due largely to a focus in public health systems on expensive, vertical, disease-specific prevention and treatment programmes, to insufficient allocation of resources to PHC (including community-based palliative care) and to lack of integration between vertical programmes and PHC (23). With the ageing of populations and the growing burden of long-term chronic illness and multiple morbidities, fragmented health care systems can no longer cope effectively with rising demands for care. These illnesses include not only cancer and major organ failure, but also HIV/AIDS and mental health conditions such as substance use disorders, depression and dementia. Disease treatment and palliative care should be integrated at all levels of health care systems. Mechanisms to ensure smooth transitions and continuity of care between various levels of health care systems, such as between hospital and home care, should be put in place for all patients, including those receiving curative treatment, chronic disease management, palliative care, and any combination of these. Integrated, accessible, people-centred PHC has been enhanced in some countries with intersectoral integration of social services such as housing, employment, family welfare and disability support programmes (24). Attention to the social determinants of ill health, and responding to social suffering with programmes such as these, are fundamental both to PHC and to palliative care and reveal their interfusion (7,25).

### Palliative care as part of PHC

Available evidence indicates that most people around the world prefer to be at home in the last phase of their life (15,26,27). To respect this preference, and to avoid or reduce overcrowding in expensive hospitals, palliative care is needed in the community and in patients' homes. Pain relief and palliative care programmes should be incorporated into existing health care systems and that palliative care be accessible in patients' homes (28). Primary care clinicians with basic training in palliative care and a set of simple, safe, effective and inexpensive medicines and equipment can respond effectively to the palliative care needs of most patients (29). However, arrangements should be put in place so that primary care clinicians can easily and reliably consult physicians with more advanced palliative care training about complex or unfamiliar problems. Arrangements also should be put in place so that clinicians at community and district levels can easily and rapidly transfer patients to a higher level institution when needed to relieve refractory suffering (30,31).

### The cost savings of integrated care

Many health problems that commonly generate referral to more expensive specialist care can be competently and adequately addressed by PHC. These problems include simple reproductive health and gynecologic problems, many non-severe communicable diseases, many chronic illnesses (including multimorbidities), uncomplicated substance use disorders and other non-complex mental health problems. They also could include uncomplicated pain or other symptoms associated with serious or life-threatening conditions. Available data indicate that palliative care integrated into PHC can be both of high quality and cost effective even in a low-income country (32). This integration also may save money for health care systems and provide financial risk protection for patients' families by reducing dependency on hospital outpatient and inpatient services (1,32–35). Involvement of CHWs and community volunteers in palliative home care also may increase social solidarity and cohesion (29).



## Specialist palliative care

Palliative care specialist physicians are needed in every country to be palliative care teachers, implementers, advisers, supervisors and consultants and to provide specialist palliative care for patients with the most complex or refractory symptoms at third-level referral hospitals. But specialist palliative care is not necessary to address the palliative care needs of most patients and families (7,27). The great majority of palliative care needs can be met by general practitioners, family physicians or non-physician health care workers in the community with basic training in palliative care or by hospital-based physician specialists in fields such as oncology or critical care who frequently care for patients with serious or life-threatening illnesses and who have intermediate-level training in palliative care as per WHO recommendations (2). Even in HICs, palliative care specialists do not provide most palliative care (11,33).

## Task shifting within PHC

General practitioners and family physicians may be the most common leaders, teachers and practitioners of PHC, especially in HICs. But professional designation is less important than competencies; task sharing and task shifting have been shown to be safe and effective ways to improve access to some PHC services. These services include treatment of hypertension diabetes mellitus, asthma, epilepsy, anxiety and depression, and screening for oral and cervical cancer (36–39). They can also include opioid therapy for moderate or severe pain due to advanced cancer or AIDS by specially trained nurses (40). Thus, appropriately trained and supervised non-physician health workers, including CHWs, can have important roles in PHC (41).

## Integrated PHC and palliative care are necessary to achieve UHC

United Nations Sustainable Development Goal 3.8 is to achieve UHC. UHC includes financial risk protection, access to quality essential health care services and access to safe, effective, quality and affordable essential medicines and vaccines for all (42). UHC is not achievable without universal access to PHC to provide essential illness prevention and treatment in the community and without universal access to community-based palliative care to provide pain and symptom control, psychosocial support and home care for patients facing serious or life-threatening illness and financial risk protection for their families (1). In most settings, universal access to community-based palliative care requires that it be integrated into PHC (7).







# 4

## Essential Package of Palliative Care for Primary Health Care

The Essential Package of Palliative Care for Primary Health Care is intended to provide health care and primary care policy-makers, planners, implementers and managers with the information needed to integrate palliative care into community-based primary care, and thereby:

- improve patient outcomes by preventing and relieving the most common and severe types of suffering associated with serious or complex health problems;
- reduce costs for health care systems by reducing hospital admissions near the end of life and length of stay;
- provide financial risk protection for patients and their families; and
- promote UHC.

The EP PHC is based on the essential package of palliative care described by Krakauer et al. (7) and Knaul et al. (1), and adapted for primary care based on the expert opinions of members of the WHO working group on palliative care in primary care. It is the minimum package that should be accessible in primary care clinics at the district or community level, and is designed to address the palliative care needs of both adults and children. It consists of:

- a set of safe, effective, inexpensive, off-patent and widely available medicines;
- simple and inexpensive equipment;
- basic social supports; and
- the human resources needed to provide the medicines, equipment and social supports effectively and safely.

Together, these elements can prevent and relieve suffering of all types – physical, psychological, social and spiritual (Table 1).

**Table 1. EP PHC: interventions, medicines, equipment, human resources, social supports**

Interventions	Inputs			
	Social support	Medicines <sup>a</sup>	Equipment	Human resources <sup>b</sup>
Prevention and relief of pain or other physical suffering, <sup>d</sup> acute or chronic		Amitriptyline, oral Bisacodyl (senna), oral Dexamethasone, oral and injectable Diazepam, oral and injectable Diphenhydramine (chlorpheniramine, cyclizine, or dimenhydrinate), oral and injectable Fluconazole, oral Fluoxetine (sertraline or citalopram), oral Furosemide, oral and injectable Haloperidol, oral and injectable Hyoscine butylbromide, oral and injectable Ibuprofen (naproxen, diclofenac or meloxicam), oral Lactulose (sorbitol or polyethylene glycol), oral Loperamide, oral Metaclopramide, oral and injectable Metronidazole, oral, to be crushed for topical use Morphine, oral immediate release and injectable Naloxone, injectable Omeprazole, oral Ondansetron, oral and injectable <sup>f</sup> Oxygen Paracetamol, oral Petroleum jelly	Pressure-reducing mattresses Nasogastric drainage and feeding tubes Urinary catheters Opioid lock boxes Flashlights with rechargeable batteries (if no access to electricity) Adult diapers or cotton and plastic	Doctors (with basic palliative care training) Nurses (with basic palliative care training) CHWs (if available)

Prevention and relief of psychological suffering, <sup>e</sup> acute or chronic		Amitriptyline, oral Dexamethasone, oral and injectable Diazepam, oral and injectable Diphenhydramine (chlorpheniramine, cyclizine or dimenhydrinate), oral and injectable Fluoxetine (sertraline or citalopram), oral Haloperidol, oral and injectable Lactulose (sorbitol or polyethylene glycol), oral	Adult diapers or cotton and plastic	Doctors (with basic palliative care training) Nurses (with basic palliative care training) Social workers, psychologists, grief counsellors, or trained and supervised lay counsellors CHWs (if available)
Prevention and relief of social suffering, acute or chronic	Income and in-kind support <sup>c</sup>			Social workers CHWs (if available)
Prevention and relief of spiritual suffering				Local spiritual counsellors

<sup>a</sup> Based on the WHO Model List of Essential Medicines 2015 (43). Acceptable alternative medicines are in parentheses: ( ).

<sup>b</sup> Doctors may be general practitioners, family doctors, paediatricians, clinical officers or assistant doctors, or others.

<sup>c</sup> Only for patients living in extreme poverty and for one caregiver per patient. Includes cash transfers to cover housing, children’s school tuition, transportation to health care facilities or funeral costs; food packages; and other in-kind support (blankets, sleeping mats, shoes, soap, toothbrushes, toothpaste).

<sup>d</sup> Other physical suffering includes breathlessness, weakness, nausea, vomiting, diarrhoea, constipation, pruritus, bleeding, wounds and fever.

<sup>e</sup> Psychological suffering includes anxiety, depressed mood, confusion or delirium, dementia and complicated grief.

<sup>f</sup> Only in hospitals that provide cancer chemotherapy or radiotherapy.

Sources: Knaul et al. 2017 (1); Krakauer et al. 2018 (7).

## Medicines

The list of medicines in the EP PHC is based on the 2015 WHO Model List of Essential Medicines for palliative care for adults and children and adapted for this document (43). Medicines were selected based on the following criteria, namely that

- they are necessary to prevent or relieve the specific symptoms or types of suffering most commonly encountered in the community (Table 1);
- their safe prescription or administration require a level of professional competency achievable by doctors, clinical officers, assistant doctors or nurses with basic training in palliative care; and
- offer the best balance in their class of accessibility on the world market, clinical effectiveness, safety, ease of use and minimal cost.

## Morphine and other opioids

Morphine, in oral fast-acting and injectable preparations, is the most clinically important of the essential palliative care medicines (44). It must be accessible in the proper form and dose by any patient with terminal dyspnea or with moderate or severe pain that is either acute, chronic and associated with malignancy, or chronic in a patient with a terminal prognosis. Opioids should not be the first-line treatment for chronic pain outside of cancer, palliative and end-of-life care, except under special circumstances and with strict monitoring (45). Morphine, in both injectable and oral fast-acting formulations, must be accessible by prescription at any hospital-based clinic. In general, at least oral fast-acting morphine should be accessible by prescription at CHCs. All doctors who provide primary care should be adequately trained and legally empowered to prescribe oral and injectable morphine for inpatients and outpatients in any dose necessary to provide adequate relief as determined by the patients. Doctors inexperienced in prescribing morphine can be trained adequately with the curriculum in basic palliative care training described in this document or similar curricula. Physicians should also be enabled to prescribe an adequate supply of morphine so that obtaining refills is feasible for patients or families without requiring unreasonably frequent, expensive or arduous travel. Whenever clinically possible, oral morphine rather than the injectable form should be prescribed. All doctors should be trained to assess and treat opioid side-effects and to avoid injudicious use of morphine for mild pain or chronic non-malignant pain. In at least one setting (Uganda), specially trained and supervised nurses are allowed to prescribe and manage morphine analgesia (41).

### **Balance: maximizing access to opioids for medical use/ minimizing risk of diversion and illicit use**

Although ensuring access to morphine for anyone in need is imperative, it also is necessary to take reasonable precautions to prevent diversion and non-medical use. Model guidelines for this purpose are available (46). Hospitals, CHCs and pharmacies should store morphine in a sturdy, locked and well-anchored box or cupboard at all times, keep records of the remaining supply, and record the amount dispensed for a patient and the amount wasted or returned by a patient's family. All personnel at these sites who handle controlled medicines such as opioids should be trained in safe storage and recordkeeping. Doctors should be trained to assess and minimize risk of opioid dependence and opioid diversion for non-medical uses. In keeping with the principle of balancing maximum accessibility of opioids for medical uses with minimum risk of opioid diversion, additional precautions might be necessary in areas with high rates of crime or violence. For example, it might not be possible to make morphine safely accessible at the community level in areas with high crime rates. In these places, accessibility must be ensured at higher levels in ways that do not unduly increase the travel burden for patients and their families. Where home or clinic supplies of morphine are frequently stolen, or patients and their families are put at risk by carrying or storing morphine, patients needing morphine might require admission to a hospital or inpatient hospice.

## Other medicines

Among the other essential palliative medicines are oral and injectable haloperidol and oral fluoxetine or another selective serotonin reuptake inhibitor (SSRI). Although these medicines are considered psychiatric or psychotropic medicines, they have multiple essential uses in palliative care and are safe and easy to prescribe. For example, haloperidol is the first-line medicine in many cases for relief of nausea, vomiting, agitation, delirium and anxiety. An SSRI, such as fluoxetine, is the first-line pharmacotherapy for depressed mood or persistent anxiety, both of which are common among people affected by humanitarian emergencies and crises (HECs). Any doctor who provides primary care should be prepared and permitted to prescribe these medicines – not solely psychiatrists or neurologists. Patients with more severe psychiatric illnesses, such as psychotic or bipolar disorders, should be referred for specialist psychiatric care whenever possible.

Petroleum jelly is essential for dressing non-healable wounds. Wet-to-dry dressings typically cause pain or bleeding when changed and can be avoided by applying petroleum jelly to dressings. Metronidazole powder, made by crushing metronidazole pills, is essential to reduce or eliminate the odor of any wound infected with anaerobic bacteria. The powder can be sprinkled on the wound or mixed with petroleum jelly or hydrogel dressings.

## Equipment

**Equipment in the EP PHC meets the following criteria. It is**

- necessary for the relief of at least one type of physical or psychological suffering
- inexpensive
- simple to use with basic training
- small enough to store easily.

The equipment includes nasogastric tubes (for vomiting refractory to medicines and for administration of medicines or fluids), urinary catheters (to manage bladder dysfunction or outlet obstruction), foam, water or air pressure-reducing mattresses (to prevent and relieve pressure ulcers and pain), locked safeboxes for opioids (to be secured to a wall or immovable object), flashlights with rechargeable batteries (when inadequate light source is available for nocturnal home care) and adult diapers or cotton and plastic bags to make adult diapers (to reduce risk of skin ulceration and infection and caregiver risk and burden). In countries where plastic bags are prohibited as part of laudable environmental protection initiatives, specialized medical use should be permitted. The EP PHC does not include materials needed for palliative care that should be standard equipment for any CHC or hospital such as gauze and tape for dressing wounds, nonsterile examination gloves, syringes and angiocatheters.

## Human resources and training

The necessary human resources depend primarily on the level and type of the health care delivery site and on the competency in palliative care of staff members rather than their professional designations. Any medical doctor, clinical officer or assistant doctor trained in basic palliative care using a curriculum such as that included in this document should be capable of preventing or relieving most pain and other physical suffering (Annex 5). They should be able to competently prescribe opioids such as morphine to treat pain for inpatients and outpatients. They also should be able to diagnose and provide pharmacotherapy as needed for uncomplicated anxiety disorders, depression or delirium. Not only doctors, nurses, psychologists and social workers, but also CHWs can be trained to provide simple, culturally appropriate psychotherapy for depression (47–50).

Occasionally, clinicians may encounter physical or psychological suffering for which they feel incapable of providing adequate treatment. Examples may include pain refractory to escalating morphine doses, depression refractory to maximum dose SSRI, or psychotic disorders. In these situations, the patient should be referred to a higher level for specialist care. If referral for appropriate specialist care is not possible, then a clinician with palliative care training should use whatever resources are available, including telemedicine, to provide the best possible care under the circumstances rather than refuse to treat.

CHWs can have a crucial role in palliative care and symptom control by visiting patients frequently at home. With as little as three to six hours of training, CHWs not only can provide important emotional support, but also recognize uncontrolled symptoms, identify unfulfilled basic needs for food, shelter or clothing or



improper use of medications, and report their findings to a nurse-supervisor at a CHC. In this way, they can accompany patients in need of palliative care and help to assure their comfort by serving as the eyes and ears of their clinicians. Based on reports from CHWs, it may be possible to arrange an appropriate response to an uncontrolled symptom, such as a change in prescription or a home visit by a nurse, that does not require the patient to leave home. Visits by CHWs also can help to reduce the often heavy emotional, physical and financial burden of family caregivers. Capable family caregivers should be trained, equipped and encouraged by clinicians to provide basic nursing care such as wound and mouth care and medicine administration. But care should be taken to assess for unmet social needs of family caregivers who typically are women and who often also have work and child-care responsibilities, frequently live in poverty.

Clinicians caring for people with serious, complex or life-limiting health problems should ask if they desire spiritual counselling. Every effort should be made to facilitate access to spiritual counselling by local volunteers that is appropriate to the beliefs and needs of the patient and family.

## Social support

Social support for patients and family caregivers living in extreme poverty is needed to ensure that their most basic needs are met such as food, housing and transport to medical care, and to promote dignity. These supports should include, as appropriate, basic food packages, housing or cash payments for housing, transportation vouchers for visits to clinics or hospitals for the patient and a caregiver, and in-kind support, such as blankets, sleeping mats, shoes, soap, toothbrushes and toothpaste. This type of social support helps to ensure that patients can access and benefit from medical care and should be accessible by any patient, not only those in need of palliative care or symptom control. One additional social support that should be accessible for families living in extreme poverty is locally adequate funeral costs. Culturally and medically appropriate burial or disposal of bodies can be a major financial burden for families, and inability to provide a funeral can become a chronic emotional burden.

## Augmenting the EP PHC

The EP PHC includes only the most basic medicines, equipment, social support and human resources that should be accessible to everyone in need. It should not be considered sufficient to meet all palliative care or symptom control needs encountered in primary care. Whenever possible, it should be augmented with medicines and equipment to optimally meet patients' needs.

### Medicines and other treatments:

- paediatric (liquid) formulations of paracetamol, ibuprofen, morphine and diazepam;
- fentanyl transdermal patches: for patients with moderate or severe cancer pain or pain near the end of life who are unable to take oral medicines or who have renal failure;
- slow-acting oral morphine: for patients with moderate or severe cancer pain or pain near the end of life who can take oral medicines; and
- access to palliative cancer treatments (radiotherapy, chemotherapy) for patients with incurable cancers.

### Equipment:

- wheelchairs, walkers and canes: to improve mobility and reduce the burden on family caregivers.



## Dying patients

When no further disease-modifying treatment is available or desired by the patient, the sole goal of care may be comfort and maximizing the quality of life. Preventing and relieving the suffering of patients dying at home is an essential task for primary care providers. Provision should be made for family members to be present as appropriate. The prognostic understanding of the patient or family should be gently explored and corrected as needed and as culturally appropriate. It should be explained that care to maximize comfort is the best that medicine can offer under the circumstances. It should be made clear that there is never an intention to hasten death but simply to provide whatever treatment is necessary to achieve an adequate level of comfort for the patient in the context of the patient's values. Aggressive efforts must be made to relieve pain and other symptoms. Patients capable of preparing a simple legacy for their children or other family members, such as a letter or memory box, should be given this opportunity. Local volunteer spiritual supporters should be sought to provide culturally appropriate spiritual support if requested by the patient or family. Bereavement support should also be made accessible (51). This may consist of bereavement support groups led by adequately trained personnel. Some interventions can be provided safely and effectively by CHWs with basic training (50).







# 5

## Implementing palliative care in primary care

### Public health strategy for palliative care

Lack of access to palliative care is a serious public health problem. Palliative care adapted to the needs of local communities and cultures should be thoroughly integrated into public health care systems (52). WHO recommends a public health strategy for integrating palliative care into health care systems in a cost-effective manner to reach all in need (2, 52, 53). This strategy entails:

- fostering political support;
- analysing palliative care needs and services;
- convening a national steering committee and obtaining agreement on an action plan;
- reviewing existing policies on palliative care and pain relief and revising them as needed or creating new ones;
- ensuring safe access to essential palliative medicines, including oral fast-acting morphine;
- initiating required training in palliative care for clinicians who treat people with palliative care needs;
- implementing palliative care services that are integrated into all health care systems at all levels; and
- measuring patient outcomes such as quality of life to ensure high quality of palliative care.

Seeking community engagement in palliative care delivery also is recommended (54). There will be modest start-up costs when implementing this strategy. For example, modest funding will be needed for the situation analysis, developing and achieving consensus for an action plan, revising or writing policies, assuring accessibility of essential medicines and establishing training programmes. In addition, funding is required to assure universal access to palliative care. However, there is evidence that palliative care, when well integrated into a health care system and including home care can save money for the health care system by reducing the need for hospital admissions near the end of patients' lives (Chapter 3) (1). Thus, over time, palliative care integration into public health care systems may pay for itself and save money thereafter.

The public health strategy for palliative care assumes a functional PHC system. Some LMICs, such as Brazil and Costa Rica, have exemplary PHC, and others, such as Rwanda, are working towards universal access to PHC (55). However, the PHC system of many LMICs is underdeveloped (56). In these settings, PHC and palliative care may be developed and expanded at the same time. The same infrastructure and human resources that provide PHC can and should provide basic palliative care, and efforts to implement community-based palliative care can and should strengthen PHC. The similarity of the principles of PHC and palliative care has enabled such collaborative implementation in Kerala, India, for example (57).

## Stepwise integration of palliative care into health care systems

Inclusion of palliative care in national health care policies is crucial. Without policies that mandate palliative care services, it is unlikely that palliative care will become widely accessible or sustainable. In general, the first steps towards integration of palliative care into health care systems should be:

- a national palliative care policy that requires access for all to palliative care and to pain control with opioid pain medicines;
- a national palliative care strategic plan to create this access within a certain time period; and
- inclusion of palliative care in any national policies or strategic plans on cancer, noncommunicable diseases (NCDs), older persons, paediatrics, HIV/AIDS, drug-resistant tuberculosis or PHC.

Once such policies and strategic plans are in place, efforts can focus on ensuring availability of all essential medicines, including oral fast-acting and injectable morphine, and on training (Chapter 4 and Annex 5). If policies do not precede training, most trainees may be unable to practise palliative care and be paid for doing so. Training can be initiated at a basic level either for primary care physicians or physicians whose specialties entail caring frequently for patients with serious or life-threatening health problems. Physicians who complete basic palliative care training should be empowered to prescribe oral fast-acting and injectable morphine for inpatients and outpatients. As soon as possible after implementing basic palliative care training for physicians, other palliative care training programmes should be established:

- intermediate-level training should be implemented for physicians whose specialties entail caring frequently for patients with serious or life-threatening health problems;
- basic palliative care training for practising nurses; and
- integration of basic training in palliative care into undergraduate medical, nursing and pharmacy training.

Next, or simultaneous with essential medicine procurement and training, palliative care services should be integrated into existing service delivery. This can begin at any level of the health care system. However, it may be easiest to implement palliative care where the need is most obvious to most staff members: in cancer centres. Initial services can be an inpatient ward, a consultation service or an outpatient clinic. National policies should require palliative care services at all cancer centres and, within a period of time, at all levels of the health care system:

- second- and third-level hospitals (provincial, regional, specialty hospitals)
- first-level (district) hospitals
- CHCs
- home care.

The palliative care interventions that should be available at each level are described in Table 2.

Table 2. Palliative care interventions, delivery platforms and providers				
Intervention	Delivery platform			
	Mobile outreach/home care	CHCs	First-level (district) hospitals	Second- and third-level (provincial, regional, specialty) hospitals
Ongoing care for patients with well-controlled symptoms related to serious, complex or life-limiting health problems	<ul style="list-style-type: none"> <li>CHWs provide surveillance and emotional support as often as daily</li> <li>Visits as needed by a nurse, doctor, social worker or trained lay counsellor from the CHC with basic training in palliative care</li> </ul>	<ul style="list-style-type: none"> <li>Nurse and possibly also a doctor, social worker or lay counsellor with basic training in palliative care provide outpatient care and possibly home visits as needed</li> <li>Inpatient hospice care in some cases if the family is unable to provide adequate care at home</li> </ul>	<ul style="list-style-type: none"> <li>Small palliative care team consisting of one or two part-time doctors with basic or intermediate training in palliative care</li> <li>Inpatient hospice care if the family is unable to provide adequate care at home and if no inpatient care is available at CHCs</li> <li>Outpatient palliative care clinic</li> </ul>	
Initial control of moderate or severe symptoms related to serious, complex or life-limiting health problems / Control of refractory suffering			<ul style="list-style-type: none"> <li>Small palliative care team consisting of one or two part-time doctors with basic or intermediate training in palliative care</li> <li>Inpatient palliative care</li> <li>Outpatient palliative care clinic</li> </ul>	<ul style="list-style-type: none"> <li>Palliative care team consisting of full- or part-time doctors with intermediate training in palliative care</li> <li>Ideally, a palliative care specialist physician should lead the team at major cancer centres and general hospitals</li> <li>Inpatient palliative care ward</li> <li>Outpatient palliative care clinic</li> </ul>

Source: Adapted from Krakauer et al. 2018 (7).

PHC practitioners who staff CHCs and district hospitals should have basic palliative care training that enables them to provide basic palliative care as part of their standard responsibilities. If possible, at least the leader of the palliative care team at district hospitals should have intermediate-level training. This would enable the team leader to serve as a resource for clinicians at CHCs in need of consultation about palliative care problems.

## Palliative care tasks in PHC

PHC, as per the Declaration of Alma-Ata, should be responsive to local needs, accessible, comprehensive, coordinated and continuous (58). To integrate palliative care into PHC, palliative care services should:

- be designed based on local needs and values;
- be accessible where the patients are and want to be, including in their homes;
- provide comprehensive prevention and relief of suffering of any kind: physical, psychological, social or spiritual;
- be coordinated with other tasks of PHC such as health promotion, disease prevention, disease-modifying or rehabilitative treatment; and
- be provided by clinicians who know the patient and family and who accompany the patient throughout the course of illness.

Palliative care needs are not the same in all places (25); however, any given patient may experience any type of suffering (59,60). In post-conflict settings, the need for mental health care may be especially great. Ideally, palliative care should be part of a system of seamlessly integrated illness prevention, early detection, treatment and rehabilitation. Ideally, PHC provides all of these services for people whose needs are uncomplicated and provides prompt referrals with secure transfer of health information and reasonable transport for patients with more complex problems.

Primary care clinicians play a crucial role in recognizing palliative care needs, including uncontrolled physical or psychological symptoms, social distress, and in identifying people approaching the end of life (61). In many low-income settings, patients may not complain of problems such as pain, anxiety or lack of food because they think nothing can be done about them. Early identification of palliative care needs by primary care providers has been found to depend on (62):

- clinicians' knowledge, skills and communication styles;
- patients' communication styles;
- quality of the clinician–patient relationship;
- patient's perceptions of the clinician's role;
- level of collaboration between the primary care clinician and other clinicians; and
- patient's fears and beliefs about the prognosis.

Skill in identifying palliative care need is crucial for primary care providers, and tools for this purpose are available. Once the need is identified, appropriate assessment and intervention can follow (61).

In integrating palliative care into PHC there is a risk of overwhelming already overburdened primary care clinicians with yet another responsibility and set of tasks (63). To avoid this, adequate funding is required



to employ an adequate number of primary care staff and thereby to strengthen the PHC system. In light of the evidence that palliative care services that include home care can reduce costs for health care systems, there are medical, ethical and financial arguments for integrating palliative care into primary care (1,7).

Another risk is that sending patients home to receive palliative care can overburden family caregivers. Caring for disabled or seriously ill patients often is extremely demanding physically, mentally and financially (32,64). Training family members in basic nursing skills may help to reduce their stress, but the home situation should be carefully assessed to make sure that the well-being of family caregivers is not jeopardized by the patient's presence at home. An alternative would be for terminally patients whose symptoms are well controlled but whose families cannot care for them at home to be allowed to receive end-of-life care at a CHC that is staffed around the clock. This would enable family to visit without having the burden of providing 24-hour care and would be less expensive than having the patient in a hospital.

## Community participation / CHWs

Community participation was identified as a component of PHC in the Declaration of Alma-Ata (65). Communities have a wealth of untapped resources and energy that can be harnessed and mobilized for health care delivery (66). In many countries, existing CHWs live in the same community as patients and can visit them at home, daily if necessary. Existing, supervised CHWs can be trained in as little as a few hours to provide emotional support, to observe for uncontrolled symptoms, unmet social needs and improper use of medicines, and to report their observations to a supervising nurse at the CHC (25). As needed, the nurse can then speak with and provide instructions to the patient or family caregiver by mobile phone. The nurse also may make a home visit and/or speak with a supervising primary care physician at the community level or a physician at the district level for advice. If necessary, the patient can be brought to the CHC or transferred to a hospital for higher-level palliative care. It is essential to establish easy and reliable methods of communication and referral between all levels of the health care system, from the home to the CHC to the hospital.

Where no CHWs exist, a network of community palliative care volunteers can be established (67). The well-being of someone in need of palliative care is a concern of many people around that person. Family members, friends, colleagues and neighbours may have an interest in ensuring the patient's comfort. In addition, compassionate people interested in the well-being of fellow human beings can be found in most communities. If these people can be identified, given rudimentary training in palliative care (and primary care) principles and organized, they can then assist the primary care team to provide and monitor palliative care (67). Some such initiatives consider chronic and incurable illnesses as biosocial problems or even as social problems with medical components rather than the commonly held reverse view (68,69).

Community participation is strongest when community members are empowered to become an integral part of the planning and implementation of PHC in their communities (70). This empowerment or capacity-building can be initiated by exploring community health care needs and describing community-based primary and palliative care at a community meeting (71).

## Training

Management of pain and other common distressing symptoms, prognostication and communication skills have been identified as basic tasks in palliative care (30). The European Association for Palliative Care (EAPC) undergraduate curriculum identifies the basics of palliative care; pain and symptom management; psychosocial and spiritual aspects; ethical and legal issues; and communication and teamwork and self-reflection as basic areas in which competence is necessary (72). In addition, it has been suggested that the palliative care team at the grassroots level ideally should have basic organizational and coordination skills (73).

The capacity to prevent and relieve suffering and to improve the quality of life of people with serious or life-threatening illnesses depends on the number, knowledge, skill and commitment of the professional and non-professional caregivers (3). People who can be involved in palliative care at the PHC level include:

- doctors/assistant doctors/clinical officers/nurse practitioners
- nurses
- social workers/psychologists/trained lay counsellors
- pharmacists
- CHWs and volunteers
- family caregivers.

Core palliative care competencies for PHC providers include (74):

- identifying early any suffering due to serious or life-threatening illness or injury;
- assessing palliative needs;
- preventing and relieving of the most common and distressing symptoms associated with serious or life-threatening illness or injury, which have been identified as (1):
  - pain
  - dyspnea
  - fatigue/weakness
  - nausea and/or vomiting
  - diarrhoea
  - constipation
  - dry mouth
  - pruritus
  - bleeding
  - wounds
  - anxiety/worry
  - depressed mood
  - confusion/delirium
  - dementia
- knowing when to refer a patient to a higher level of care; and
- providing emotional support and future care planning for patients and families that is sensitive to each patient's and family's culture, values and prior experiences with death.

WHO suggests training requirements for PHC staff members who provide palliative care as follows (3).

Doctors, clinical officers, assistant doctors, nurse practitioners, feldshers:

- minimum: basic course (30–40 hours)
- ideal: intermediate-level course (60–80 hours).

Nurses:

- minimum: basic course (30–40 hours)
- ideal: intermediate-level course (60–80 hours).

Implementers or leaders of community-based or mobile palliative care teams (doctors or nurses):

- 5–6-week course focused on developing palliative care services:
  - Example: the Palliative Care Initiators' Course offered by Hospice Africa Uganda <http://uganda.hospiceafrica.or.ug/index.php/int-l-programmes/initiator-courses>

See Annex 5 for sample curricula for doctors, nurses and CHWs.

CHWs and volunteers:

- minimum: 3–6 hours (for established, supervised CHWs):
  - Example: a workbook for training CHWs, volunteers and family carers from the Institute of Palliative Care in Kerala, India, a WHO Collaborating Centre (75) <http://www.instituteofpalliativemedicine.org/downloads/Palliative%20Care%20Workbook%20for%20Carers.pdf>; topics include:
    - What is palliative care?
    - carers' responsibilities to patients/community participation in palliative care;
    - productive interaction with the system;
    - knowing about the patient's biomedical, psychosocial and spiritual status;
    - knowing how to communicate to the patient in a supportive way;
    - knowing the basics of nursing care;
    - knowing when and where to seek help for the patient and carer (including oneself); and
    - grief and bereavement.
- rudimentary training in palliative care principles and policies can be complemented by supervised practical experience working with PHC professionals in providing care (66, 71).

To prepare the health care work force of the future, all medical students and nursing students should have a 30–40-hour basic course in palliative care in the final year of their training. Basic courses in palliative care should be made available as part of continuing education to clinicians already practising PHC. They should be given incentives to obtain this training, and a deadline could be set by which time all PHC providers should have completed the basic palliative care training.

## Task shifting

WHO has developed a series of global recommendations for task shifting of palliative care services for patients with HIV/AIDS (76). These principles may be useful in deciding which members of PHC teams can provide which palliative care services more generally (Table 3).

**Table 3. PHC workers who can provide specific palliative care services**

	Medical doctor	Non-physician clinician	Nurse	Community health worker
<b>Pain management</b>				
Conduct pain assessments	x	x	x	x
Treat mild, moderate and severe pain using chronic pain management guidelines, including oral morphine	x	x	x	
Teach the patient and caregiver how to give pain medicine, including oral morphine	x	x	x	x
Prevent, recognize and treat the side-effects of pain medications	x	x	x	
Advise on non-pharmacological methods of controlling pain	x	x	x	x
Treat extreme, non-responsive pain appropriately, including through the use of steroids where indicated	x	x		
<b>Symptom management</b>				
Manage other common symptoms (weight loss, nausea, fever, diarrhoea, trouble sleeping, anxiety etc.)	x	x	x	
<b>Psychosocial support and end-of-life care</b>				
Counselling, psychosocial and spiritual support	x	x	x	x
Support for patient at end of life	x	x	x	x
Support for caregivers, family members and children	x	x	x	x
<b>Supervision</b>				
Supervise non-physician clinicians, nurses and community health workers in above activities	x			
Supervise nurses and community health workers in above activities	x	x		
Supervise community health workers in above activities	x	x	x	

Source: WHO 2016 (3).

When task shifting, it is crucial that supervision be provided regularly and be continually available to maintain a high quality of care.

## Box 2. North-east Thailand: palliative care integrated into PHC

Thailand has a three-tiered public health care system: primary care units; district hospitals; and provincial hospitals. Of the population, 99% is covered through a universal health insurance. Thailand's exceptionally good record in health and human development is based on heavy investment in health infrastructure, particularly PHC, and on extending financial risk protection to the poor and vulnerable, public and private sector employees, and those engaged in the informal economy (77,78). In north-east Thailand, the Ministry of Public Health has developed a network of nurse-led palliative home care teams within the public health care system. A Palliative Care Training Centre in a university hospital trains and organizes the nurse-led home care teams that are then based at the provincial hospitals, district hospitals and primary care units (community health centers/CHCs). After a successful pilot project, the programme was extended throughout north-east Thailand encompassing 20 provincial hospitals, 300 district hospitals and more than 3000 CHCs. The home care teams are supervised by palliative care units that now exist in 95% of the district hospitals. The palliative care units in district hospitals link with the palliative care units at the provincial hospital and with the CHCs (78). This success was possible because of the existence of:

- a strong PHC network;
- a national programme for UHC; and
- an effective training programme at a palliative care training centre.

## Box 3. Uganda: community-based palliative care with minimal integration into PHC

Uganda was the first country in the world to enable specially trained and registered nurses to prescribe morphine (79) and it was one of only two African countries in the top 50 of the Economist Intelligence Unit's 2015 Quality of Death Index (80). It achieved this ranking despite an underfunded and underdeveloped public health care system. Nongovernmental organizations (NGOs) play a major role in providing palliative care at the community level. Basic palliative services now exist in 75% of the countries districts. However, these services often are provided by only one trained nurse at only one site in a district, which may be quite large (81). Palliative care is not yet well integrated into the public health care system at all levels (82). Barriers to this integration include inadequate health infrastructure, shortage of trained palliative care staff, and insufficient and unstable funding (83).

## Box 4. Kerala, India: integration of palliative care into PHC using a public health approach

The state of Kerala in southern India has integrated palliative care into much of its well-developed PHC system. In this state of 33 million people, an NGO in the city of Calicut created a palliative care service for the poor in the early 1990s. The success of its leaders at fostering community participation throughout the state resulted in a Neighbourhood Network in Palliative Care (NNPC). Inspired by the concept of PHC in the Declaration of Alma-Ata, the NNPC is an attempt to empower local communities in LMICs to create and manage sustainable long-term and palliative care for the poor (67,84). Volunteers from communities receive training to identify problems of the chronically ill in their area and to intervene effectively with active support from a network of trained professionals. Based on the rapid growth and popularity of NNPC supported only by NGOs and local governments, the Government of Kerala in 2008 issued a pain and palliative care policy that included a commitment to integrate palliative care into the existing PHC system (85). The government followed this policy with a project to inform doctors and nurses, from all levels of the health care system, as well as local politicians and potential community volunteers, about palliative care for the most vulnerable as part of community-based PHC. The goal was to stimulate the development of palliative care programmes by local governments fostering community spirit. The project also provided six months of training in palliative care for nurses and hired one trained nurse for each panchayat (community) in the state. As of 2017, all the 1000 PHC centres in Kerala had a government nurse trained in palliative care who typically leads a home care programme staffed by local volunteers. Some 200 of the panchayat have created local NGOs that increase the capacity of palliative home care, and some support the salary of a second palliative care nurse who collaborates with the government nurse. In addition, palliative care units are being developed in the 14 district hospitals in the public health care system to support the staff of PHC centres.

The following factors have contributed to the success of the programme:

- advocacy by local NGOs about the imperative of caring for the chronically and terminally ill poor, resulting in:
  - large-scale involvement by local people and communities; and
  - political commitment by the state government;
- state government policy on palliative care as part of PHC;
- state funding for palliative care nurses in PHC centres;
- decentralized system of governance in Kerala with empowered local governments; and
- use of nurses, home care leaders.







## 6

## Ensuring access to essential controlled medicines

Strong opioids such as morphine are essential for the treatment of pain due to cancer, HIV/AIDS and other serious illnesses, or due to traumatic injuries, burns and surgery. Yet despite being included on the WHO Model List of Essential Medicines, morphine has not been accessible at all times in adequate amounts, in the appropriate dosage forms, with assured quality and adequate information, and at a price the individual and the community can afford (43). Of the world's population, 75% lacks access to morphine or another strong opioid when clinically indicated to treat pain. WHO estimates that 5.5 million terminal cancer patients and 1 million end-stage HIV/AIDS patients worldwide suffer each year without adequate treatment for moderate to severe pain.

International drug regulatory bodies, such as the INCB, have acknowledged that their emphasis historically has been on restricting opioid misuse and abuse, rather than on ensuring the medical availability of opioids (86). Yet the United Nations Single Convention on Narcotic Drugs, which virtually all nations have signed, states that nations must both minimize the risk of abuse and diversion of opioids and ensure their availability for medical and scientific purposes. This dual obligation of governments is called the principle of balance, a principle that has been affirmed by WHO (43,87,88), the United Nations Commission on Narcotic Drugs and the United Nations General Assembly. Governments should ensure that all physicians involved in patient care are both legally permitted and institutionally authorized to prescribe and administer strong opioids such as morphine according to the medical needs of patients. Governments also should ensure that a sufficient supply of morphine is available to meet all medical needs. While misuse of controlled substances poses a risk to society, the system of control is not intended to be a barrier to their availability for medical and scientific purposes, nor interfere in their legitimate medical use for patient care.

To fulfil the requirements of the Single Convention and of acceptable medical practice, every effort should be made to identify the barriers to opioid availability within each country. Typically, these barriers include:

- overly restrictive regulations on opioid prescribing and dispensing;
- inadequate education of doctors, nurses and pharmacists in pain control and the appropriate use of opioids; and
- lack of understanding of the appropriate use of opioids among drug regulators who often focused only on reducing the risk of misuse and abuse and not at all on making these medicines available.

Examples of overly restrictive regulations include (44):

- a requirement that physicians purchase special opioid prescription pads;
- a requirement that all opioid prescriptions for outpatients be signed not only by the prescribing physician, but also by a supervisor or an anaesthesiologist;
- permitting only specifically designated physicians to prescribe opioids;
- permitting only specialist physicians to prescribe opioids and not general practitioners or family doctors;
- setting a low maximum daily dose of opioid that may be prescribed and a low maximum amount that may be prescribed and dispensed; and
- restricting opioids to patients who are receiving hospice services.

All health systems should establish a system to monitor the flow of opioids from import or manufacture to use by the patient (89). In the inpatient setting, there should be verification of opioids taken by the patient. In the outpatient setting, there should be verification of opioids handed over by a pharmacist or clinician to the patient or to a family member on behalf of the patient, minus any amount returned to the pharmacy or clinician by the patient or family. Such a system should not interfere with access to opioids for medical uses, but rather ensure continued availability of these medicines. So-called stockouts and other supply chain failures result in patients suffering both from opioid withdrawal symptoms and from pain, and can increase risk of illicit opioid use and suicide (90).

The Single Convention requires all countries to report annual opioid consumption to the INCB. Together with other health statistics, this reporting is crucial for estimating a country's expected opioid need in the next year and for the INCB to officially allocate the amount needed (91). The INCB has defined various methods for countries to calculate their expected need. Increases in allocation from one year to the next can be requested based on, for example, expected improvements in health care services or on revised estimates of disease prevalence. The INCB uses the pooled estimates from all countries to ensure that the appropriate quantity of opioids is available globally.





# 7

## Integration of palliative care strengthens public health systems and promotes UHC

Well-planned integration of palliative care into public health care systems can improve their performance, reduce costs and promote UHC (1). Palliative care networks that entail home care linked with and supervised by hospital-based inpatient and/or outpatient palliative care units can do more than improve the quality of life of patients. Data from HICs and high-middle-income countries show that such networks also can reduce length of stay in hospitals and enable many patients to remain at home or in the community, thereby reducing unnecessary hospital admissions for symptom control and relief, particularly near the end of life (7). Hence, palliative care can reduce hospital overcrowding and costs for overburdened health systems and provide financial risk protection for patients and their families (92–101). Within hospitals, the presence of a palliative care inpatient unit also can improve patients' quality of life and reduce costs, in part by reducing use of life-sustaining treatments and cancer chemotherapy near the end of life that likely are harmful rather than beneficial as well as expensive (102–104). While no such studies from low- and low-middle-income countries have been reported yet, it appears that the start-up costs necessary to integrate people-centred palliative care services into health care systems – policy development, essential medicine procurement, training and increasing staffing – may pay dividends over time by improving patient outcomes, reducing costs for the health care system, and reducing dysfunctional overuse of hospitals and non-beneficial interventions.

Integration of palliative care specifically into PHC can yield additional benefits. Palliative home care should be provided in most cases as part of the PHC system by expanding home care services provided particularly by CHWs or nurses. Visiting patients at home presents an ideal opportunity both to inquire about the well-being of the household and family and to educate them. Nurses as well as CHWs can be trained to provide education not only on caregiving for the patient, but also, for example, on smoking cessation, indoor air quality, HIV prevention and the importance of a healthy diet, exercise, prenatal care and screening for cervical cancer. In addition, inquiring about the well-being of household and family members can promote earlier recognition of tuberculosis, cancer and other illnesses as well as social problems such as lack of food, school tuition for children or decent housing. Thus, integration of palliative care into PHC systems also can strengthen the system's capacity for health promotion, disease prevention and early recognition of disease (25, 105).

Integration of palliative care into PHC also may improve disease treatment outcomes (106). PHC systems with enhanced home care capacity due to integration of palliative care can provide visits to patients in advance of an appointment for chemotherapy, radiotherapy or oncology follow-up to make sure the patient has the means and intention of keeping it. During visits, palliative home care staff also can promote adherence to outpatient treatment of myriad illnesses, including breast cancer, HIV/AIDS, tuberculosis, hypertension and diabetes mellitus. In general, palliative home care visits can help to prevent loss-to-follow-up of patients receiving palliative care and of their family members who also are receiving health care.









## 8

## Need for research and quality improvement

Ministries of health and health care planners can estimate the palliative care needs in their countries or regions with existing documents such as the WHO Global atlas of palliative care at the end of life and the report of the Lancet Commission on palliative care and pain relief (1, 11). However, accurate locally generated data are more helpful to precisely characterize the health requirements of a given population and to inform health care planning. Reliable data can provide information about the principal health challenges facing a population and about treatment outcomes, making it easier for health systems to prioritize investment of scarce resources. To optimize the benefit of palliative care integrated into PHC, it is useful to understand the suffering of the target populations by means of a palliative care situation analysis. It also is important to understand local attitudes to infirmity, suffering, dying and death. In addition, it is important to measure the safety, effectiveness, value, and acceptability of palliative care once it is implemented.

### Situation analysis

#### Data on needs, values and beliefs of patients in the community

To design palliative care services that provide optimum benefit for a specific population, the most common and most severe types of suffering should be studied. When no such data exist on the target population, palliative care situation analyses can assess all categories of suffering: physical; psychological; social; and spiritual. The target population may be small or large. It may be just one community, clinic population or hospital (25, 107, 108) or it may be an entire region or country (109, 110). The situation analysis may use multiple detailed surveys (110), or it may use only one short survey. Ideally, data on types of suffering should be collected directly from patients rather than from family members or clinicians. However, many patients who are having discomfort or are near the end of life are unable to participate in long surveys. Thus, there is a benefit to using very concise surveys that nevertheless address all types of suffering. One example is the Palliative Outcomes Scale that exists in several forms for various populations and has been validated in several languages (111, 112). This instrument can yield useful information both for researchers and for clinicians. It is brief enough to be incorporated into routine hospital or clinic forms for recording patient history and physical examination, and these forms, whether electronic or hardcopy, can be used both for palliative care situation analysis and quality assurance, assuming appropriate research ethics regulations are followed (25).

Attitudes towards disability, suffering, dying, death and palliative care can also be studied with standardized surveys. While no assumptions should be made about any individual patient based on ethnicity, religion, perceived culture, sex, education or any other demographic parameter, and each patient's views and values should be explored, understanding of attitudes and values common in a target population is important for developing optimum palliative care training and services (113). Guidance is available on how to design such research that is based on issues relevant to potential users, for example, patients and carers, and thereby to avoid waste (114). Involving the community in setting research agendas is recommended (115).

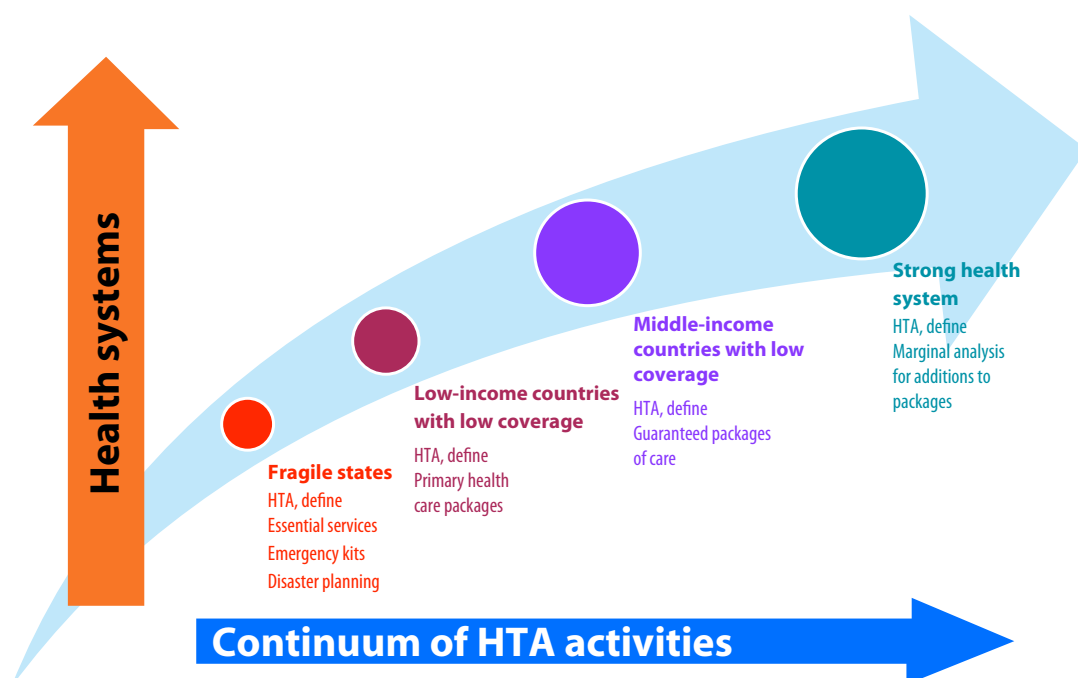
## Ongoing data collection on palliative care integration, accessibility, quality and outcomes

The degree of integration of palliative care into a health care system, and its accessibility, may be assessed with a few output measures such as those developed by WHO for its periodic survey of NCD country capacity around the world (116). Such a study might explore:

- whether government funding is provided for palliative care within primary care;
- whether there is a national policy that includes palliative care and whether a national policy on primary care includes palliative care;
- whether such policies are operational, under development, or not in effect;
- whether oral morphine is available in over 50% of the primary care facilities of the public health sector;
- whether palliative care is accessible by over 50% of patients in PHC in the public health system; and
- whether palliative home care is accessible by over 50% of patients in PHC in the public health system.

To assess periodically the quality and outcomes of palliative care, the same instruments used for palliative care situation analyses can often be used. Where feasible, however, WHO endorses health technology assessment (HTA) to systematically evaluate the properties, effects and/or impacts of health interventions (Figure 1) (117). HTA covers both the direct, intended consequences of interventions and their indirect, unintended consequences. The approach is used to inform policy and decision-making in health care, especially on how best to allocate limited funds to health interventions. The assessment is conducted by interdisciplinary groups using explicit analytical frameworks, drawing on clinical, epidemiological, health economic and other information and methodologies. It may be applied to interventions, such as home care in public health insurance coverage, rolling out broad public health programmes such as palliative care, priority setting in health care, identifying health interventions that produce the greatest health gain and offer value for money, and formulating clinical guidelines.

**Figure 1. Health technology assessment: a tool to inform decision-makers in support of UHC**



Source: <http://www.who.int/health-technology-assessment/about/en/>

All providers of palliative care, whatever the care setting, should be committed to continuous improvement of the quality of their services. Data collected from quality indicators are a primary source of information for improving services. A basic framework for indicators that can be used to assess the key domains of national or regional programmes is described in Table 4.

**Table 4. Sample indicators for assessing enhanced access to palliative care in PHC**

Category	Indicator
<b>Policy</b>	Existence of a current national palliative care policy that requires access for all to palliative care and to pain control with opioid pain medicines (yes/no)
	Existence of a current national palliative care strategic plan to create access for all within a specified time period to palliative care and to pain control with opioid pain medicines (yes/no)
	Existence of current national policies or strategic plans that promote access to palliative care and to opioid analgesia on the following topics: <ul style="list-style-type: none"> <li>■ primary health care (yes/no)</li> <li>■ cancer (yes/no)</li> <li>■ noncommunicable diseases (yes/no)</li> <li>■ older persons (yes/no)</li> <li>■ paediatrics (yes/no)</li> <li>■ HIV/AIDS (yes/no)</li> <li>■ drug-resistant tuberculosis (yes/no)</li> </ul>
	Essential Package of Palliative Care for Primary Health Care included in universal health coverage (yes/no)
	Laws and regulations in place for safe and effective opioid prescribing in line with international drug conventions at the district level? (yes/no)
	At the community level? (yes/no)
<b>Education</b>	Proportion of medical schools that include palliative care education in undergraduate curricula (ratio of medical schools with palliative care at the undergraduate level to total medical schools)
	Proportion of nursing schools that include palliative care education in undergraduate curricula (ratio of nursing schools with palliative care at the undergraduate level to total nursing schools)
	Proportion of medical technical schools (for training clinical officers, assistant doctors, nurse practitioners or feldshers) that include palliative care education in undergraduate curricula (ratio of medical technical schools with palliative care to total medical technical schools)
<b>Service provision</b>	Palliative care included in the list of services provided at the primary care level (yes/no)
	Proportion of communities that provide palliative care services (ratio of the number of communities that provide palliative care services to the total number of communities)
<b>Medicines</b>	Consumption of strong opioids per cancer death (milligrams of oral morphine equivalents per patient who dies from cancer)
	All WHO essential medicines for palliative care included on the national list of essential medicines (yes/no)
	Proportion of districts where oral morphine is in stock and available in at least one pharmacy (ratio of districts with oral morphine in stock and available to the total number of districts)
<b>Outcomes</b>	Percentage of patients with access to palliative care at the time of death
	Number of patients receiving palliative care per 100 000 inhabitants

Sources: Adapted from WHO 2016 (3) and Knaul et al. 2017 (1).



## Additional proposed indicators of the effectiveness and value of palliative care integration into PHC

Standard health metrics such as the quality-adjusted life year (QALY) and disability-adjusted life year (DALY) do not adequately measure some important objectives of health systems, including prevention and relief of patient's suffering and financial risk protection and poverty reduction for patients and their families (118). To address this short-coming, two new research concepts have been proposed:

1. A method of health policy assessment – extended cost-effectiveness analysis (ECEA) – would enable a broader assessment of the effect on the well-being of both patients and families of a policy for integrating palliative care into PHC. ECEA examines public policies, whether health or intersectoral policies, that have an impact on the health of populations. Specifically, it evaluates the health and financial consequences of public policies in four domains: (i) health gains; (ii) financial risk protection benefits for patients and their families; (iii) total costs to the policy-makers; and (iv) distributional or equity benefits (1,119).
2. A measurement of suffering-adjusted life-years (SALYs) might provide crucial information beyond that contained in existing measures of burden of ill health (QALYs and DALYs) (1).

## Palliative care-related knowledge and attitudes of PHC providers and CHWs

Exploration of the knowledge and attitudes of PHC providers and CHWs about providing palliative care may yield useful information for integrating palliative care integration into PHC (Annexes 6 and 7). For example, it has been shown that primary care physicians tend not to identify palliative care needs early in the course of a life-limiting illness. Exploration of the reasons for this phenomenon may be useful to enhance access to palliative care for those in need (62,120). In particular, their self-assessment of competencies in identifying and responding to social, spiritual and legal problems could be explored (121). Knowledge and attitudes of primary care providers about advance care planning could yield useful culture-specific information (122-125). To develop and refine training for CHWs, and to support them in their work, their palliative care-related knowledge and attitudes also should be studied (126).

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# Annexes

## Annex 1

### Declaration of Alma-Ata (1978) (66)

The International Conference on Primary Health Care, meeting in Alma-Ata this twelfth day of September in the year Nineteen hundred and seventy-eight, expressing the need for urgent action by all governments, all health and development workers, and the world community to protect and promote the health of all the people of the world, hereby makes the following declaration:

**I** The Conference strongly reaffirms that health, which is a state of complete physical, mental and social wellbeing, and not merely the absence of disease or infirmity, is a fundamental human right and that the attainment of the highest possible level of health is a most important world-wide social goal whose realization requires the action of many other social and economic sectors in addition to the health sector.

**II** The existing gross inequality in the health status of the people, particularly between developed and developing countries, as well as within countries is politically, socially and economically unacceptable and is, therefore, of common concern to all countries.

**III** Economic and social development, based on a New International Economic Order, is of basic importance to the fullest attainment of health for all and to the reduction of the gap between the health status of the developing and developed countries. The promotion and protection of the health of the people is essential to sustained economic and social development and contributes to a better quality of life and to world peace.

**IV** The people have the right and duty to participate individually and collectively in the planning and implementation of their health care.

**V** Governments have a responsibility for the health of their people which can be fulfilled only by the provision of adequate health and social measures. A main social target of governments, international organizations and the whole world community in the coming decades should be the attainment by all peoples of the world by the year 2000 of a level of health that will permit them to lead a socially and economically productive life. Primary health care is the key to attaining this target as part of development in the spirit of social justice.

**VI** Primary health care is essential health care based on practical, scientifically sound and socially acceptable methods and technology made universally accessible to individuals and families in the community through their full participation and at a cost that the community and country can afford to maintain at every stage of their development in the spirit of self-reliance and self-determination. It forms an integral part both of the country's health system, of which it is the central function and main focus, and of the overall social and economic development of the community. It is the first level of contact of individuals, the family and community with the national health system bringing health care as close as possible to where people live and work, and constitutes the first element of a continuing health care process.

**VII** Primary health care:

1. reflects and evolves from the economic conditions and sociocultural and political characteristics of the country and its communities and is based on the application of the relevant results of social, biomedical and health services research and public health experience;

2. addresses the main health problems in the community, providing promotive, preventive, curative and rehabilitative services accordingly;
3. includes at least: education concerning prevailing health problems and the methods of preventing and controlling them; promotion of food supply and proper nutrition; an adequate supply of safe water and basic sanitation; maternal and child health care, including family planning; immunization against the major infectious diseases; prevention and control of locally endemic diseases; appropriate treatment of common diseases and injuries; and provision of essential drugs;
4. involves, in addition to the health sector, all related sectors and aspects of national and community development, in particular agriculture, animal husbandry, food, industry, education, housing, public works, communications and other sectors; and demands the coordinated efforts of all those sectors;
5. requires and promotes maximum community and individual self-reliance and participation in the planning, organization, operation and control of primary health care, making fullest use of local, national and other available resources; and to this end develops through appropriate education the ability of communities to participate;
6. should be sustained by integrated, functional and mutually supportive referral systems, leading to the progressive improvement of comprehensive health care for all, and giving priority to those most in need;
7. relies, at local and referral levels, on health workers, including physicians, nurses, midwives, auxiliaries and community workers as applicable, as well as traditional practitioners as needed, suitably trained socially and technically to work as a health team and to respond to the expressed health needs of the community.

**VIII** All governments should formulate national policies, strategies and plans of action to launch and sustain primary health care as part of a comprehensive national health system and in coordination with other sectors. To this end, it will be necessary to exercise political will, to mobilize the country's resources and to use available external resources rationally.

**IX** All countries should cooperate in a spirit of partnership and service to ensure primary health care for all people since the attainment of health by people in any one country directly concerns and benefits every other country. In this context the joint WHO/UNICEF report on primary health care constitutes a solid basis for the further development and operation of primary health care throughout the world.

**X** An acceptable level of health for all the people of the world by the year 2000 can be attained through a fuller and better use of the world's resources, a considerable part of which is now spent on armaments and military conflicts. A genuine policy of independence, peace, détente and disarmament could and should release additional resources that could well be devoted to peaceful aims and in particular to the acceleration of social and economic development of which primary health care, as an essential part, should be allotted its proper share. The International Conference on Primary Health Care calls for urgent and effective national and international action to develop and implement primary health care throughout the world and particularly in developing countries in a spirit of technical cooperation and in keeping with a New International Economic Order. It urges governments, WHO and UNICEF, and other international organizations, as well as multilateral and bilateral agencies, nongovernmental organizations, funding agencies, all health workers and the whole world community to support national and international commitment to primary health care and to channel increased technical and financial support to it, particularly in developing countries. The Conference calls on all the aforementioned to collaborate in introducing, developing and maintaining primary health care in accordance with the spirit and content of this Declaration.

## Annex 2

### Sixty-second World Health Assembly resolution WHA62.12 on Primary health care, including health system strengthening

22 May 2009

The Sixty-second World Health Assembly,

Welcoming the efforts of the Director-General, and recognizing the pivotal role that WHO plays in promoting primary health care globally; Having considered the report on primary health care, including health system strengthening; Reaffirming the Declaration of Alma-Ata (1978) and the United Nations Millennium Declaration (2000); Recalling the Ottawa Charter for Health Promotion (1986) and subsequent relevant resolutions of WHO regional committees and health assemblies; Recalling also the discussions at the series of summits and global, regional and national conferences that have reaffirmed the commitment of Member States to primary health care and strengthening health systems; Noting the growing consensus in the global health community that vertical approaches, such as disease-specific programmes, and integrated health systems approaches are mutually reinforcing and contribute to achieving the health-related Millennium Development Goals; Recognizing the need to draw on the experiences, both positive and negative, of primary health care in the years since the Declaration of Alma-Ata and the Millennium Declaration;

Welcoming the World health report 2008, published on the thirtieth anniversary of the international conference of Alma-Ata, that identifies four broad policy directions for reducing health inequalities and improving health for all: tackling health inequalities through universal coverage, putting people at the centre of care, integrating health into broader public policy, and providing inclusive leadership for health; and also welcoming the final report of the Commission on Social Determinants of Health;

Reaffirming the need to build sustainable national health systems, strengthen national capacities, and honour fully financing commitments made by national governments and their development partners, as appropriate, in order to better fill the resource gaps in the health sector;

Reaffirming also the need to take concrete, effective and timely action, in implementing all agreed commitments on aid effectiveness and to increase the predictability of aid, while respecting recipient countries' control and ownership of their health system strengthening, more so given the potential effects on health and health systems of the current international financial and food crises and of climate change;

Strongly reaffirming the values and principles of primary health care, including equity, solidarity, social justice, universal access to services, multisectoral action, decentralization and community participation as the basis for strengthening health systems;

#### 1. Urges Member States:

- (1) to ensure political commitment at all levels to the values and principles of the Declaration of Alma-Ata, keep the issue of strengthening health systems based on the primary health care approach high on the international political agenda, and take advantage, as appropriate, of health-related partnerships and initiatives relating to this issue, particularly to support achievement of the health-related Millennium Development Goals;
- (2) to accelerate action towards universal access to primary health care by developing comprehensive health services and by developing national equitable, efficient and sustainable financing mechanisms, mindful of the need to ensure social protection and protect health budgets in the context of the current international financial crisis;

- (3) to put people at the centre of health care by adopting, as appropriate, delivery models focused on the local and district levels that provide comprehensive primary health care services, including health promotion, disease prevention, curative care and palliative care, that are integrated and coordinated according to needs, while ensuring effective referral system;
- (4) to promote active participation by all people, and re-emphasize the empowering of communities, especially women, in the processes of developing and implementing policy and improving health and health care, in order to support the renewal of primary health care;
- (5) to train and retain adequate numbers of health workers, with appropriate skill mix, including primary health care nurses, midwives, allied health professionals and family physicians, able to work in a multidisciplinary context, in cooperation with non-professional community health workers in order to respond effectively to people's health needs;
- (6) to encourage that vertical programmes, including disease-specific programmes, are developed, integrated and implemented in the context of integrated primary health care;
- (7) to improve access to appropriate medicines, health products and technologies, all of which are required to support primary health care;
- (8) to develop and strengthen health information and surveillance systems, relating to primary health care in order to facilitate evidence-based policies and programmes and their evaluation;
- (9) to strengthen health ministries, enabling them to provide inclusive, transparent and accountable leadership of the health sector and to facilitate multisectoral action as part of primary health care;

## 2. Requests the Director-General:

- (1) to ensure that WHO reflects the values and principles of the Declaration of Alma-Ata in its work and that the overall organizational efforts across all levels contribute to the renewal and strengthening of primary health care, in accordance with the findings of the Commission on Social Determinants of Health;
- (2) to strengthen the Secretariat's capacities, including capacities of regional and country offices, to support Member States in their efforts to deliver on the four broad policy directions for renewal and strengthening of primary health care identified in The world health report 2008;
- (3) to collate and analyse past and current experiences of Member States in implementing primary health care and facilitate the exchange of experience, evidence and information on good practice in achieving universal coverage, access and strengthening health systems;
- (4) to foster alignment and coordination of global interventions for health system strengthening, basing them on the primary health care approach, in collaboration with Member States, relevant international organizations, international health initiatives, and other stakeholders in order to increase synergies between international and national priorities;
- (5) to ensure adequate funding for health system strengthening and revitalizing primary health care in the Programme budget 2010–2011;
- (6) to prepare implementation plans for the four broad policy directions: (1) dealing with inequalities by moving towards universal coverage; (2) putting people at the centre of service delivery; (3) multisectoral action and health in all policies; (4) inclusive leadership and effective governors for health; to ensure that these plans span the work of the entire Organization, and to report on these plans through the Executive Board to the Sixty-third World Health Assembly and subsequently on progress every two years thereafter.

## Annex 3

### Sixty-ninth World Health Assembly resolution WHA69.24 on Strengthening integrated, people-centred health services

28 May 2016

The Sixty-ninth World Health Assembly,

Having considered the follow-up of the report on the framework on integrated, people-centred health services;

Acknowledging Sustainable Development Goal 3 (Ensure healthy lives and promote well-being for all at all ages) including target 3.8, which addresses achieving 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;

Recalling resolution WHA64.9 (2011) on sustainable health financing structures and universal coverage, which urged Member States to continue investing in and strengthening health-delivery systems, in particular primary health care and services, and adequate human resources for health and health information systems, in order to ensure that all citizens have equitable access to health care and services;

Reaffirming resolution WHA62.12 (2009) on primary health care, including health system strengthening, which requested the Director-General to prepare implementation plans for four broad policy directions, including putting people at the centre of service delivery, and also reaffirming the need to continue to prioritize progress on the implementation plans on the other three broad policy directions included in resolution WHA62.12: (1) dealing with inequalities by moving towards universal coverage; (2) multisectoral action and health in all policies; and (3) inclusive leadership and effective governors for health;

Recalling resolution WHA63.16 (2010) on the WHO Global Code of Practice on the International Recruitment of Health Personnel and its recognition that an adequate and accessible health workforce is fundamental to an integrated and effective health system, and to the provision of health services;

Recalling also resolution WHA64.7 (2011) on strengthening nursing and midwifery, which emphasized the implementation of strategies for enhancement of interprofessional education and collaborative practice as part of people-centred care, and resolution WHA66.23 (2013) on transforming health workforce education in support of universal health coverage;

Reaffirming resolution WHA60.27 (2007) on strengthening health information systems, which acknowledged that sound information is critical in framing evidence-based health policy and making decisions, and fundamental for monitoring progress towards internationally agreed health-related development goals;

Recalling resolution WHA67.20 (2014) on regulatory system strengthening for medical products, resolution WHA67.21 (2014) on access to biotherapeutic products, including similar biotherapeutic products, and ensuring their quality, safety and efficacy, resolution WHA67.22 (2014) on access to essential medicines, resolution WHA67.23 (2014) on health intervention and technology assessment in support of universal health coverage and resolution WHA67.18 (2014) on traditional medicine,

#### 1. **Adopts the framework on integrated, people-centred health services;**

## **2. Urges Member States:**

- (1) to implement, as appropriate, the framework on integrated, people-centred health services at regional and country levels, in accordance with national contexts and priorities;
- (2) to implement proposed policy options and interventions for Member States in the framework on integrated, people-centred health services in accordance with nationally set priorities towards achieving and sustaining universal health coverage, including with regard to primary health care as part of health system strengthening;
- (3) to make health care systems more responsive to people's needs, while recognizing their rights and responsibilities with regard to their own health, and engage stakeholders in policy development and implementation;
- (4) to promote coordination of health services within the health sector and intersectoral collaboration in order to address the broader social determinants of health, and to ensure a holistic approach to services, including health promotion, disease prevention, diagnosis, treatment, disease-management, rehabilitation and palliative care services;
- (5) to integrate, where appropriate, traditional and complementary medicine into health services, based on national context and knowledge-based policies, while assuring the safety, quality and effectiveness of health services and taking into account a holistic approach to health;

## **3. Invites international, regional and national partners to take note of the framework on integrated, people-centred health services;**

## **4. Requests the Director-General:**

- (1) to provide technical support and guidance to Member States for the implementation, national adaptation and operationalization of the framework on integrated, people-centred health services, paying special attention to primary health services as part of health system strengthening;
- (2) to ensure that all relevant parts of the Organization, at headquarters, regional and country levels, are aligned, actively engaged and coordinated in promoting and implementing the framework on integrated, people-centred health services;
- (3) to perform research and development on indicators to trace global progress on integrated people-centred health services;
- (4) to report on progress on the implementation of the framework on integrated people-centred health services to the Seventy-first and Seventy-third World Health Assemblies and at regular intervals thereafter.

## Annex 4

### Sixty-seventh World Health Assembly resolution WHA67.19 on Strengthening of palliative care as a component of comprehensive care throughout the life course

24 May 2014

The Sixty-seventh World Health Assembly,

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

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

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

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

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

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

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

Affirming that access to palliative care and to essential medicines for medical and scientific purposes manufactured from controlled substances, including opioid analgesics such as morphine, in line with the three United Nations international drug control conventions,<sup>4</sup> contributes to the realization of the right to the enjoyment of the highest attainable standard of health and well-being;

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

<sup>1</sup> Document 67/31.

<sup>2</sup> Document E/INCB/2010/1/Supp.1.

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

<sup>4</sup> United Nations Single Convention on Narcotic Drugs, 1961, as amended by the 1972 Protocol; United Nations Convention on Psychotropic Substances, 1971; United Nations Convention against Illicit Traffic in Narcotic Drugs and Psychotropic Substances, 1988.



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

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

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

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

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

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

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

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

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

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

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

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

### 1. Urges Member States:<sup>5</sup>

to develop, strengthen and implement, where appropriate, palliative care policies to support the comprehensive strengthening of health systems to integrate evidence-based, cost-effective and equitable palliative care services in the continuum of care, across all levels, with emphasis on primary care, community and home-based care, and universal coverage schemes;

to ensure adequate domestic funding and allocation of human resources, as appropriate, for palliative care initiatives, including development and implementation of palliative care policies, education and training, and quality improvement initiatives, and supporting the availability and appropriate use of essential medicines, including controlled medicines for symptom management;

to provide basic support, including through multisectoral partnerships, to families, community volunteers and other individuals acting as caregivers, under the supervision of trained professionals, as appropriate;

to aim to include palliative care as an integral component of the ongoing education and training offered to care providers, in accordance with their roles and responsibilities, according to the following principles:

- (a) basic training and continuing education on palliative care should be integrated as a routine element of all undergraduate medical and nursing professional education, and as part of in-service training of caregivers at the primary care level, including health care workers, caregivers addressing patients' spiritual needs and social workers;
- (b) intermediate training should be offered to all health care workers who routinely work with patients with life-threatening illnesses, including those working in oncology, infectious diseases, paediatrics, geriatrics and internal medicine;
- (c) specialist palliative care training should be available to prepare health care professionals who will manage integrated care for patients with more than routine symptom management needs;

to assess domestic palliative care needs, including pain management medication requirements, and promote collaborative action to ensure adequate supply of essential medicines in palliative care, avoiding shortages;

to review and, where appropriate, revise national and local legislation and policies for controlled medicines, with reference to WHO policy guidance,<sup>6</sup> on improving access to and rational use of pain management medicines, in line with the United Nations international drug control conventions;

to update, as appropriate, national essential medicines lists in the light of the recent addition of sections on pain and palliative care medicines to the WHO Model List of Essential Medicines and the WHO Model List of Essential Medicines for Children;

to foster partnerships between governments and civil society, including patients' organizations, to support, as appropriate, the provision of services for patients requiring palliative care;

<sup>5</sup> And, where applicable, regional economic integration organizations.

<sup>6</sup> Ensuring balance in national policies on controlled substances: guidance for availability and accessibility of controlled medicines. Geneva: World Health Organization; 2011.

to implement and monitor palliative care actions included in WHO's global action plan for the prevention and control of noncommunicable diseases 2013–2020;

## **2. Requests the Director-General:**

to ensure that palliative care is an integral component of all relevant global disease control and health system plans, including those relating to noncommunicable diseases and universal health coverage, as well as being included in country and regional cooperation plans;

to update or develop, as appropriate, evidence-based guidelines and tools on palliation, including pain management options, in adults and children, including the development of WHO guidelines for the pharmacological treatment of pain, and ensure their adequate dissemination;

to develop and strengthen, where appropriate, evidence-based guidelines on the integration of palliative care into national health systems, across disease groups and levels of care, that adequately address ethical issues related to the provision of comprehensive palliative care, such as equitable access, person-centred and respectful care, and community involvement, and to inform education in pain and symptom management and psychosocial support;

to continue, through WHO's Access to Controlled Medicines Programme, to support Member States in reviewing and improving national legislation and policies with the objective of ensuring balance between the prevention of misuse, diversion and trafficking of controlled substances and appropriate access to controlled medicines, in line with the United Nations international drug control conventions;

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

to work with the International Narcotics Control Board, the United Nations Office on Drugs and Crime, health ministries and other relevant authorities in order to promote the availability and balanced control of controlled medicines for pain and symptom management;

to further cooperate with the International Narcotics Control Board to support Member States in establishing accurate estimates in order to enable the availability of medicines for pain relief and palliative care, including through better implementation of the guidance on estimating requirements for substances under international control;<sup>7</sup>

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

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

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

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

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

<sup>7</sup> International Narcotics Control Board, World Health Organization. Guide on estimating requirements for substances under international control. New York: United Nations; 2012.

## Annex 5

### Sample curricula in palliative care for primary health care (PHC) providers

#### Sample A: Basic curriculum for training doctors, clinical officers, assistant doctors, nurse practitioners

##### Day 1

- 1.1 Palliative care basic training course: goals and agenda  
Slide presentation
- 1.2 Epidemiology of serious and life-threatening health problems in the country  
Slide presentation
- 1.3 Palliative care: definition, principles, accessibility, and moral imperative  
Slide presentation
- 1.4 Palliative care assessment: approach to the patient in need of palliative care  
Slide presentation
- 1.5 Ethical issues and patient-doctor communication in palliative care: principles and practice  
Slide presentation
- 1.6 Giving bad news  
Role play in small groups

##### Day 2

- 2.1 Pain assessment and treatment: Part 1  
Slide presentation
- 2.2 Pain assessment and treatment: Part 2  
Slide presentation
- 2.3 Neurobiology of pain  
Slide presentation
- 2.4 Opioid policy and barriers to opioid analgesia  
Slide presentation
- 2.5 Pain cases  
Small group discussion

##### Day 3

- 3.1 Dyspnea assessment and treatment  
Slide presentation
- 3.2 Dyspnea case  
Small group discussion

3.3 Nausea/vomiting assessment and treatment

Slide presentation

3.4 Constipation/diarrhoea assessment and treatment

Slide presentation

3.5 Gastrointestinal symptom case

Small group discussion

3.6 Constitutional symptoms assessment and treatment

Slide presentation

3.7 Dermatology in palliative care

Slide presentation

## Day 4

4.1 Psychological distress in the seriously ill: depression and anxiety

Slide presentation

4.2 Altered mental status: delirium and dementia

Slide presentation

4.3 Loss, grief and bereavement

Slide presentation

4.4 Social and spiritual suffering

Large group discussion

4.5 Psychosocial assessment and support in palliative care

Slide presentation and small group role play

4.6 Professional resilience

Short lecture and large group discussion

4.8 Memorial ceremony

Group activity

## Day 5

5.1 Palliative care needs and available services in the country

Slide presentation

5.2 Integrating palliative care into the health care system: global models

Slide presentation/discussion

5.3 Palliative care strategic planning: What can you do in your home institution?

Group work and discussion

Final examination

Source: Global Program of Harvard Medical School Center for Palliative Care and Massachusetts General Hospital, 2017.

## Sample B: Basic curriculum for training nurses

### Day 1

- 1.1 What is palliative care? Definition and principles  
Lecture/discussion
- 1.2 Palliative care situation in the country  
Lecture/discussion
- 1.3 The palliative care team  
Lecture/discussion
- 1.4 Roles of nurses in palliative care  
Lecture/discussion
- 1.5 Nursing ethics in palliative care  
Lecture/discussion
- 1.6 Palliative care assessment and approach to the patient  
Lecture/discussion/role play

### Day 2

- 2.1 Principles of pain management  
Lecture/discussion
- 2.2 Side-effects of pain medicines  
Lecture/discussion
- 2.3 Instructing patients and family-caregivers on correct use of morphine  
Lecture/discussion
- 2.4 Subcutaneous injection and infusion procedures  
Lecture/demonstration
- 2.5 Pain control cases  
Small group discussion

### Day 3

- 3.1 Dyspnea: assessment and management  
Lecture/discussion
- 3.2 Dyspnea case  
Small group discussion
- 3.3 Wounds, oedema, and skin problems: assessment and management  
Lecture/discussion/demonstration
- 3.4 Nausea/vomiting: assessment and management  
Lecture/discussion
- 3.5 Constipation/diarrhoea: assessment and management  
Lecture/discussion

3.6 Other symptoms: loss of appetite, cachexia, fever  
Lecture/discussion

3.6 GI symptom cases  
Small group discussion

#### **Day 4**

4.1 Psychological/psychiatric problems: assessment and management  
Lecture/discussion

4.2 Agitated patient case  
Large group discussion

4.3 Patient–nurse relationship, communication, and breaking bad news  
Lecture/discussion

4.4 Discussing diagnosis and prognosis with patient or family  
Small group role play

4.5 Loss, grief, bereavement  
Lecture/discussion

4.6 Emotional support for dying patients and their families  
Lecture/discussion/role play

4.7 Health care worker self-care  
Lecture/discussion/group activity

#### **Day 5**

5.1 Barriers to pain relief in the country  
Lecture/discussion

5.2 Implementing palliative care nursing in participants' home institutions  
Lecture/group work/discussion

Final examination

*Sources:* University of Medicine & Pharmacy at Ho Chi Minh City, Viet Nam; Global Program of Harvard Medical School Center for Palliative Care at Massachusetts General Hospital, 2017.



## Sample C: Basic curriculum for training community health workers (CHWs)

4 Hours: 8 sessions of 30 minutes

1. What is palliative care?  
Brief presentation/sharing of experiences with incurable illness in family/friends
2. CHW's responsibilities to the patient  
Brief presentation/discussion
3. Knowing about the patient's medical, psychosocial and spiritual status  
Presentation/discussion
4. Knowing how to communicate to the patient in supportive ways  
Presentation/discussion
5. Knowing how to recognize uncontrolled symptoms  
Presentation/Q&A
6. Knowing when and how to report to supervisor and seek help  
Presentation/Q&A
7. Resilience and self-care  
Brief presentation/discussion
8. Grief and bereavement support  
Brief presentation/discussion

*Source:* Adapted from the Institute of Palliative Medicine. Palliative care – a workbook for carers. Calicut, Kerala, India: WHO Collaborating Centre for Community Participation in Palliative Care and Long Term Care, 2017.

## Annex 6

### Links

#### **World Health Organization**

- Palliative Care Programme

<http://www.who.int/palliativecare/en/>

- Guidelines on persisting pain in children

[http://www.who.int/medicines/areas/quality\\_safety/guide\\_perspainchild/en/](http://www.who.int/medicines/areas/quality_safety/guide_perspainchild/en/)

- Planning and implementing palliative care services: a guide for programme managers

[http://www.who.int/ncds/management/palliative-care/palliative\\_care\\_services/en/](http://www.who.int/ncds/management/palliative-care/palliative_care_services/en/)

- Global atlas of palliative care at the end of life

<http://www.who.int/ncds/management/palliative-care/palliative-care-atlas/en/>

#### **World Hospice Palliative Care Alliance**

<http://www.thewhpc.org/>

#### **Pain and Policy Studies Group**

<http://www.painpolicy.wisc.edu/>

#### **International Association for Hospice and Palliative Care (IAHPC)**

<https://hospicecare.com/home/>

#### **International Children's Palliative Care Network**

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

#### **African Palliative Care Association (APCA)**

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

#### **Latin American Palliative Care Association**

<http://www.cuidadospaliativos.org/>

#### **Asia Pacific Hospice Palliative Care Network**

<http://aphn.org/>

**European Association for Palliative Care**

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

**European Association for Palliative Care (EAPC) Primary Care Reference Group**

<http://www.eapcnet.eu/Themes/ProjectsTaskForces/EAPCReferenceGroups/PrimaryCare.aspx>

**World Organization of National Colleges, Academies and Academic Associations of General Practitioners/Family Physicians (WONCA)**

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

## Annex 7

### Glossary

#### **Bereavement support**

Psychological or spiritual counselling or other emotional support for a person grieving after the death of a loved one.

#### **Community health workers (CHWs)**

CHWs are members of the community where they work, should be selected by the community, should be answerable to the community for their activities, should be supported by the health system but not necessarily be a part of it, and have shorter training than professional health workers.

#### **Health systems strengthening**

The process of identifying and implementing the changes in policy and practice in a country's health system, so that the country can respond better to its health and health system challenges. Any array of initiatives and strategies that improves one or more of the functions of the health system and that leads to better health through improvements in access, coverage, quality or efficiency.

#### **Hospice**

An organization or institution devoted entirely to providing inpatient or outpatient palliative care for patients nearing the end of life.

#### **Integrated health services**

Health services that are managed and delivered in a way that ensures people receive a continuum of health promotion, disease prevention, diagnosis, treatment, disease management, rehabilitation and palliative care services, at the different levels and sites of care within the health system, and according to their needs throughout their life course.

#### **Internally displaced persons (IDPs)**

People forced to flee their homes but who never cross an international border. These individuals seek safety anywhere they can find it – in nearby towns, schools, settlements, internal camps, even forests and fields. IDPs, which include people displaced by internal strife and natural disasters, are the largest group that the United Nations High Commissioner for Refugees (UNHCR) assists. Unlike refugees, IDPs are not protected by international law or eligible to receive many types of aid because they are still legally under the protection of their own country.

#### **Intersectoral action**

The inclusion of several sectors, in addition to health, when designing and implementing public policies that seek to improve health care and quality of life.

## **People-centred health services**

Health services designed to incorporate the perspectives of individuals, families and communities. They are based on the conviction that individuals, families and communities are participants in – as well as beneficiaries of – trusted health systems that respond to their needs and preferences in humane and holistic ways. People-centred care requires that people have the education and support they need to make decisions and participate in their own care. It is organized around the health needs and expectations of people rather than diseases.

## **Refugee**

Someone who has been forced to flee his or her country because of persecution, war or violence. A refugee has a well-founded fear of persecution for reasons of race, religion, nationality, political opinion or membership of a particular social group. Most likely, the person cannot return home or is afraid to. War and ethnic, tribal and religious violence are leading causes of refugees fleeing their countries.

## **Serious health-related suffering (SHS)**

Suffering is health-related when it is associated with illness or injury of any kind. Suffering is serious when it cannot be relieved without medical intervention and when it compromises physical, social or emotional functioning. Palliative care should be focused on relieving SHS associated with life-limiting or life-threatening conditions, or the end of life.

## **Social determinants of health**

The conditions in which people are born, grow, live, work and age. These circumstances are shaped by the distribution of money, power and resources at global, national and local levels, and they are mostly responsible for health inequities – the unfair and avoidable differences in health status seen within and between countries.

## **Universal health coverage (UHC)**

Health coverage that provides people with the health services they need while protecting them from exposure to financial hardship incurred in obtaining care. Health services are broadly defined to include health promotion initiatives (such as anti-tobacco policies or emergency preparedness), disease prevention activities (such as vaccination) and the provision of treatment, rehabilitation and palliative care (such as symptom relief and end-of-life care) of sufficient quality to be effective.



**World Health  
Organization**

**World Health Organization  
20, Avenue Appia  
1211 Geneva 27  
Switzerland**

**<http://www.who.int/servicedeliverysafety/en>**

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