Integrating palliative care and symptom relief into paediatrics

A WHO guide for health care planners, implementers and managers

World Health Organization

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

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Abbreviations and acronyms

AIDS	acquired immunodeficiency virus
APCA	African Palliative Care Association
CFHI	Child Friendly Healthcare Initiative
CHC	community health centre
CHW	community health worker
EAPC	European Association for Palliative Care
EP Ped	Essential Package of Palliative Care for Paediatrics and Symptom Relief
GP	general practitioner
HIC	high-income country
HIV	human immunodeficiency virus
ICPCN	International Children's Palliative Care Network
IDT	interdisciplinary [palliative care] team
INCB	International Narcotics Control Board
LMIC	low- and middle-income country
MoH	Ministry of Health
NCD	noncommunicable disease
NGO	nongovernmental organization
PHC	primary health care
PPC	paediatric palliative care
SDG	Sustainable Development Goal
SSRI	selective serotonin reuptake inhibitor
UHC	universal health coverage
UN	United Nations
WHA	World Health Assembly
WHO	World Health Organization

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Foreword

The World Health Assembly has resolved that providing access to palliative care for children is "an ethical responsibility of health systems" and that integration of palliative care into public health-care systems is essential for achievement of the Sustainable Development Goal on universal health coverage (WHA 67.19). Yet access to paediatric palliative care and symptom relief is very rare in a number of countries. As a result, millions of the world's vulnerable children suffer unnecessarily each year.

A wide range of childhood health problems can generate the need for palliative care and symptom relief including not only advanced noncommunicable disease and HIV/AIDS, but also severe prematurity, birth trauma, congenital anomalies, severe non-progressive disabilities such as paraplegia and quadriplegia, drug-resistant tuberculosis and injuries. Paediatric palliative care requires special knowledge and skills, and it is essential that all providers of primary health care for children and paediatric specialty care possess these competencies.

This document 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. The current publication is intended to assist anyone involved with planning, implementing, managing or assuring the quality of health care for children to integrate palliative care and symptom relief such that the quality of life of children and their families will be improved, health-care systems will be strengthened and cost-effective models of service provision will be implemented.

With this guide, WHO reiterates its commitment to answering the needs and expectations of all people, especially the most vulnerable.

Introduction

People younger than 20 years comprise 35% of the global population and 40% of the global population of least-developed nations *(1)*. The number of children – neonates, infants, children, and adolescents up to 19 years of age – who need pediatric palliative care (PPC) each year may be as high as 21 million *(2)*. Another study found that almost 2.5 million children die each year with serious health-related suffering and that more than 98% of these children are in low- and middle-income countries (LMICs) *(3)*. While estimates differ, there is no doubt that there is an enormous need for prevention and relief of suffering among children – for PPC. In response to the large-scale unnecessary suffering of children, the 2014 World Health Assembly resolution WHA67.19 on Strengthening of palliative care as a component of comprehensive care throughout the life course emphasizes that access to palliative care for children is an "ethical responsibility of health systems" (Annex 4) *(4)*. Remarkably, however, PPC has not been seen as a priority around the world. A 2011 study found no PPC services in 65.6% of countries *(5)*. Where services do exist in LMICs, they typically are available in only one or a few institutions and are not integrated into health care systems. A review of PPC in sub-Saharan African countries found that less than 1% of children needing palliative care in Kenya had access to it and less than 5% in South Africa and Zimbabwe *(6)*.

This guide is part of a series of World Health Organization (WHO) guidance documents on palliative care *(7)*. It describes the medical and moral necessity of making palliative care and pain relief accessible to all children in need, and their families. It offers an expanded conception of PPC based on the needs of children in LMICs as well as in high-income countries (HICs). It also proposes an Essential Package of Palliative Care for Paediatrics and Symptom Relief (EP Ped) and provides practical guidance on integrating PPC and pain relief into health care systems such that the quality of life of children and their families is improved, health care systems are strengthened and cost-effective models of service provision are implemented, all of which contribute to the goal of universal health coverage (UHC).

This document is not a clinical manual, and it does not provide clinical guidelines. Rather, its contents are relevant to anyone involved with planning, implementing or managing PPC, including officials of United Nations (UN) organizations working with children, Ministry of Health (MoH) officials, public health leaders, hospital managers, nongovernmental organizations (NGOs), general and specialist paediatricians, surgeons, anaesthesiologists, primary care providers and palliative care providers. It has been developed by a working group of experts in PPC and symptom relief from around the world with extensive experience in working in LMICs.

1 What is paediatric palliative care?

Part 1. Defining 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 *(8)*. These problems include the physical, psychological, social and spiritual suffering of patients, and psychological, social and spiritual suffering of family members.

Palliative care *(9)*:

- 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, complex 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;
- is applicable to those living with long-term physical, psychological, social or spiritual sequelae of serious, complex or life-limiting illnesses or of their treatment;
- accompanies bereaved family members after the patient's death;
- 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 of various kinds, 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, strengthens health systems and promotes UHC.

The specific types and severity of suffering vary according to geopolitical situation, socioeconomic conditions and culture. Children and their families in LMICs often endure unhealthy social conditions. They also typically have less access to disease prevention, diagnosis and treatment, to social supports and to specialists and specialized services of many kinds than children in HICs. For example, many children have

limited or no access to cancer chemotherapy, radiation therapy or oncologic surgery, to effective treatment for multidrug-resistant tuberculosis or to neonatal or paediatric intensive care. Palliative care should never be considered a substitute for disease prevention and treatment or for critical care, and palliative care workers have a responsibility to advocate for them wherever they are not yet accessible *(9,10,11)*. But palliative care also should be universally accessible *(4)*.

Many countries also lack rehabilitation medicine specialists and services and long-term care facilities to care for children 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 address 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 suffering and of suffering due to non-life-threatening conditions often are inadequate or unavailable. For example, in countries where pain medicine does not yet exist as a specialty and where few doctors prescribe opioid pain medicines, prevention and relief of pain from trauma or burns or surgery typically are inadequate. Thus, in these settings, clinicians trained in palliative care could fill this therapeutic void either by training colleagues in symptom control, by providing direct symptom relief, or both.

Planning and implementing palliative care services should 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 *(3,12)*.

Table 1. Type of suffering and palliative care need

Patient population	HICs palliative care need	LMICs palliative care need
Advanced chronic NCDs	High	High
HIV/AIDS	Moderate	Very high
Drug-resistant tuberculosis	Very low	High in some regions
Critical illness	High	High
Neonates with severe prematurity, birth trauma or congenital anomaly	High	Very high
Severe non-progressive disabilities such as paraplegia and quadriplegia	Moderate	High
Severe social distress such as extreme poverty or stigmatization	Low	High
Acute symptoms related to illness, injuries, surgery	Not applicable	High
Health emergencies and crises	Very low	High in some areas

Part 2. How does palliative care differ between children and adults?

Children are not just little adults. While the definition and principles of palliative care in Part 1 of this chapter apply to the entire lifespan, PPC requires attention to physical, developmental, psychosocial, ethical, spiritual and relational phenomena that are unique to children (Table 2). Salient differences between adults and children for PPC include the following.

- **Passage through the different development stages**

  Children change continually as they grow from neonates to adolescents. Children undergo marked physical change, learn to talk, mature in their ability to understand illness and become more independent and self-reliant. Because children proceed at different speeds through the many developmental milestones, palliative care providers should become adept at assessing the unique developmental stage and needs of each child and at responding appropriately. Children who have grown up with chronic illness, interacting with clinicians and hospitals, tend to have a more mature understanding of illness, death and dying than children of their age who have been healthy most of their lives.

- **Communication needs**

  Good communication with patients and their families requires sensitivity to the child's developmental stage and to the language, culture and illness understanding of both the patient and family and to their degree of trust in the health care system. To the greatest extent possible, PPC elicits a child's report of her/his symptoms using, for example, validated paediatric pain scales. PPC also honours each child's values as much as possible and seeks their uncoerced direction, alongside that of the family, about treatments and goals of care. Patients who have not yet reached maturity or the legal age of consent sometimes may disagree with their parents or family caregivers about these issues.

- **Dependence on adults**

  Children's dependence on others ranges from the total dependence of a neonate to the high degree of independence of some adolescents who may sometimes want to be seen as a child when seriously ill.

- **Impact on families**

  While a child's serious or life-threatening illness profoundly impacts any family, the impact may be greatest in LMICs. Even where treatment is provided free of charge or mostly covered by insurance, the illness can result in financial hardship or catastrophe for the family. Co-payments for treatment, or gratuities may in themselves strain or exceed a family's financial capabilities. In addition, families must pay for travel to the clinic or hospital not only for the patient, but also for a family caregiver. If the patient remains in the hospital, the family caregiver – often a parent or older child – must pay for meals and often also a place to sleep. That parent or older child is then unable to work and care for the household. This may result in siblings being taken out of school either for lack of school fees or because they must work or care for younger siblings. To pay these expenses, families must often sell their possessions, including farm animals, land, tools or machines needed to earn a living, or even their homes. Too often, a child's illness results in the family's financial impoverishment as well *(13–15)*. PPC must assess these risks and respond to them with social supports (Chapter 4).

  Even when the family's financial situation is stable, the emotional impact of a child's serious or life-threatening illness is usually profound. The emotional distress of parents whose child is experiencing serious or life-threatening illness typically is much greater than for a family member of an adult with a similarly serious condition. Parents often seek any treatment that might help their child, even

if it takes them far from home and far exceeds their financial resources. Thus, PPC entails taking time to explore parents' understanding of their child's diagnosis and prognosis and to gently correct misunderstandings. Parents have reported that they might have made different decisions if they had understood earlier what they understood after their child had died. In addition, each family has unique psychosocial characteristics. A child with a life-threatening disease may strain or challenge existing relationships within the family. Role reversal, overly enmeshed relationships, and alliances and conflicts between family members may occur. A dysfunctional family may significantly impair the child's quality of life. PPC includes assessment of family function and efforts to resolve conflict or dysfunction.

- **Types of health conditions**

  The wide range of childhood illnesses increases the difficulty of providing PPC services that meet each child's needs. Further, many paediatric genetic or congenital conditions are rare and not seen in adults, the symptoms may differ in each child and there may be no clear diagnosis or prognosis *(16*).

- **Paediatric formulations and dosing of essential medicines**

  It is easier to provide the correct weight-based dose for a young child of a liquid formulation of a medicine, and it is easier for a child to swallow. Where no liquid or paediatric formulation of an essential medicine such as oral morphine is accessible, pills may be cut in halves or quarters or crushed and mixed with food or dissolved in liquid. However, it is difficult to provide an accurate dose in this manner. Further, the pharmacokinetics of medicines are often different in children than in adults, but there may be little or no evidence on the safety and effectiveness of some palliative medicines in children. When there is no alternative to a given medicine to relieve a child's symptom, particular judiciousness and vigilance are needed on the part of the clinician *(17)*.

- **Degree of difficulty of clinical decision-making**

  Decision-making about using, withholding or withdrawing disease-modifying or life-sustaining treatments of questionable benefit for a child can be especially difficult for a variety of reasons. Parents often have more difficulty understanding or accepting the poor prognosis of a child than of an aged family member. Clinicians, too, may find it most difficult to weigh the relative benefits and burdens of an intervention when the patient is a child. In addition, modes of decision-making for ill children unable to speak for themselves often vary by culture, by family and sometimes even within families. Whenever possible, gentle but diligent efforts should be made to understand the child's perspective.

- **Clinical environment**

  PPC wards and clinics should be made as child-friendly and comforting as possible. The comfort of paediatric patients can be promoted by enabling at least one family member to be present and comfortable (to have adequate food and a comfortable place to sleep near the patient at an affordable cost). The child's comfort also can be enhanced with distracting pictures or soothing colors on the wall, comforting and clean textures on the bedding, gentle sounds such as soft music or lullabies, or calming toys.

Table 2. PPC: differences from adult palliative care

- Prognosis, life expectancy and functional outcome often less clear.
- More frequent need to integrate palliative care with intensive disease-modifying or life-sustaining treatments due to unclear prognosis.
- Care often requires a dual focus on growth/development and potential for death.
- Greater emotional burden for family members and clinicians because serious and life-threatening illnesses are not commonly considered normal conditions for children.
- Patients undergo continual developmental change: physical, hormonal, cognitive, expressive and emotional.
- Patients have changing information needs, recreational and educational needs, and modes of coping with stress. Thus, child life specialists, play therapists and behavioural specialists can greatly enhance palliative care for children.
- Patients may have congenital anomalies of uncertain type or rare genetic conditions.
- Some genetic conditions may affect multiple children in a family and create a sense of guilt in parents.
- Expertise needed both to discern a child's emotional and cognitive development and to communicate in a manner appropriate for the child's emotional and cognitive development: to provide the most appropriate amount and kind of information about the illness and to elicit the child's preferences for care.

Sources: Adapted from Levine et al. 2013 *(18)* and Weaver et al. 2016 *(19)*.

Part 3. Who requires PPC?

Children with a wide range of health conditions require PPC (Tables 3 and 4). Thus, PPC should be integrated into all sectors and all levels of child health care, and it should be integrated with many types of potentially curative and life-sustaining treatments (Chapter 5) *(20,21)*. In addition, clear plans should be put in place to make sure palliative care continues without interruption when children with long-term palliative care needs become adults. In LMICs, efforts to integrate palliative care into health care systems should always be accompanied by efforts to maximize accessibility of prevention, early diagnosis and treatment of serious and life-threatening illnesses *(21,22)*. However, this accessibility is very limited for many children in LMICs *(5,23–25)*. In addition, as many as 80% of malignancies and many cases of organ failure are diagnosed very late in their course when curative treatment is not available in the country or does not exist *(26–28)*. Therefore, the need for PPC is greatest in LMICs, yet few PPC services exist in these countries (Chapter 2).

Table 3. Populations that need PPC

Population	Examples
Children with acute life-threatening conditions from which recovery may or may not be possible	Any critical illness or injury, severe malnutrition
Children with chronic life-threatening conditions that may be cured or controlled for a long period but that may also cause death	Malignancies, multidrug-resistant tuberculosis, HIV/AIDS
Children with progressive life-threatening conditions for which no curative treatment is available	Spinal muscular atrophy, Duchenne's muscular dystrophy
Children with severe neurologic conditions that are not progressive but may cause deterioration and death	Static encephalopathy, spastic quadriplegia, spina bifida
Neonates who are severely premature or have severe congenital anomalies	Severe prematurity, anencephaly, congenital diaphragmatic hernia, trisomy 13 or 18
Family members of a fetus or child who dies unexpectedly	Fetal demise, hypoxic-ischaemic encephalopathy, overwhelming sepsis in a previously healthy child, trauma from motor vehicle accident, burns, . . .

Sources: Downing et al. 2016 *(29)*; Wood et al. 2010 *(30)*.

Table 4. Conditions that commonly generate a need for PPC

Condition	Examples of palliative care needs
Malignancies (paediatric types differ from those in adults)	■ Leukaemias: haemorrhage due to coagulopathies, painful procedures such as bone marrow biopsies ■ Brain tumour: headache, cognitive and neurologic deficits ■ Sarcomas: severe pain, loss of a limb
Conditions discovered or occurring in the perinatal period *(31–33)*	■ Congenital anomalies: symptomatic dysfunction of a vital organ such as the heart, bowel or brain; stigmatized superficial anomalies ■ Prematurity: respiratory distress, intraventricular haemorrhage, brain ischaemia and permanent neurodevelopmental disability ■ Birth asphyxia: hypoxic-ischaemic brain injury and permanent neurodevelopmental disability
Injuries	■ Head trauma: poor cognitive and motor skills ■ Burns: acute and sometimes also chronic pain, stigmatized disfigurement ■ Exposure to violence, conflict or natural hazard: mood disorders such as anxiety, depression, post-traumatic stress disorder
Serious infections	■ HIV/AIDS: symptomatic opportunistic infections, stigmatization, adverse effects of medicines ■ Drug-resistant tuberculosis: cough, constitutional symptoms (fever, sweats, weight loss), adverse effects of medicines, social isolation, stigmatization ■ Meningitis: permanent neurodevelopmental disability ■ Rheumatic fever: symptomatic heart failure
Genetic conditions	■ Neurologic conditions: progressive neurological deficits and disability ■ Sickle cell disease and anaemia: pain crises, bone necrosis ■ Connective tissue disorders: chronic pain

Protein energy malnutrition	■ Pain, dyspnea ■ Vomiting or diarrhoea related to re-feeding
Being a patient	■ Painful procedures ■ Postoperative pain ■ Not having an opportunity to have questions answered and fears assuaged

Sources: Adapted from Knaul et al. 2017 *(3)* and Krakauer et al. 2018 *(22)*.

Part 4. "Palliative care plus": preventing and relieving the suffering of children without a life-threatening illness

Attentively identifying, preventing and managing a child's pain is a moral and ethical imperative, regardless of the patient's age (even neonates experience pain), ability to communicate or cognitive capacity, or health condition *(22,34)*. Where acute and procedural pain control and services for children with severe disabilities or congenital anomalies are readily available, as they often are in HICs, palliative care can focus entirely on children with life-threatening illnesses. However, where these services are not easily accessible, as is often the case in LMICs, clinicians trained in palliative care should provide them, or teach others to provide them, in addition to caring for children with life-threatening illnesses.

Acute and procedural pain

Acute pain from traumatic injuries is often inadequately treated in children or not treated at all. The result is not only unnecessary suffering from the pain itself, but also greater emotional distress on the part of the child and family, greater difficulty in treating the patient due to pain-related fear and agitation, and a higher risk of chronic emotional sequelae such as post-traumatic stress disorder *(35)*. Procedural pain is a common yet preventable cause of suffering in children. For quick and minimally invasive procedures such as phlebotomy, simple non-pharmacologic techniques can be used before, during and after the procedures to minimize pain and its associated fear and distress. Distraction or relaxation techniques prior to and during painful procedures can help patients and caregivers maintain a sense of control and decrease the perceived intensity of symptoms. Topical analgesia also can be used, if available. For more complex procedures, such as burn dressing changes, systemic analgesia medication should be used. Intra-operative and postoperative pain usually require an opioid.

Examples of painful procedures:

- phlebotomy
- injections
- lumbar puncture
- bone marrow aspirate
- thoracentesis
- dressing changes.

Children who suffer without a clearly life-threatening condition

There is a large burden of suffering among children with severe physical disabilities in both HICs and LMICs. Although the range of diagnoses is large and diverse, there are common types of suffering experienced by children with disabilities that can be relieved through palliative care approaches *(36)*. Whether the disability is due to a traumatic injury, congenital anomaly or genetic condition, pain and social isolation and stigmatization are common. Other chronic physical or psychological symptoms may be present depending on the specific condition. In addition, whenever a child (or adult) is permanently unable to feed or wash herself, walk or use the toilet independently, this may cause physical, financial and emotional burdens for the family, especially a rural poor family. Palliative care providers may be the only source of relief for these types of distress.

Box 1. Child Friendly Healthcare Initiative (CFHI)

CFHI is based on the United Nations Convention on the Rights of the Child (UNCRC) (Annexes 1 and 3) and was developed by Child Advocacy International (CAI) with the technical support of WHO, the Royal College of Nursing (United Kingdom) and the Royal College of Paediatrics and Child Health (United Kingdom) in collaboration with the United Nations Children's Fund (UNICEF). The main aim of CFHI is to develop a system of care focused on the physical, psychological and emotional well-being of children attending health care facilities, particularly as inpatients. A set of globally applicable standards were proposed to ensure that practices in hospitals and health centres everywhere respected children's rights, not only relating to survival and avoidance of morbidity, but also in relation to their protection from unnecessary suffering and their informed participation in treatment *(37)*.

2 Access to palliative care and symptom relief

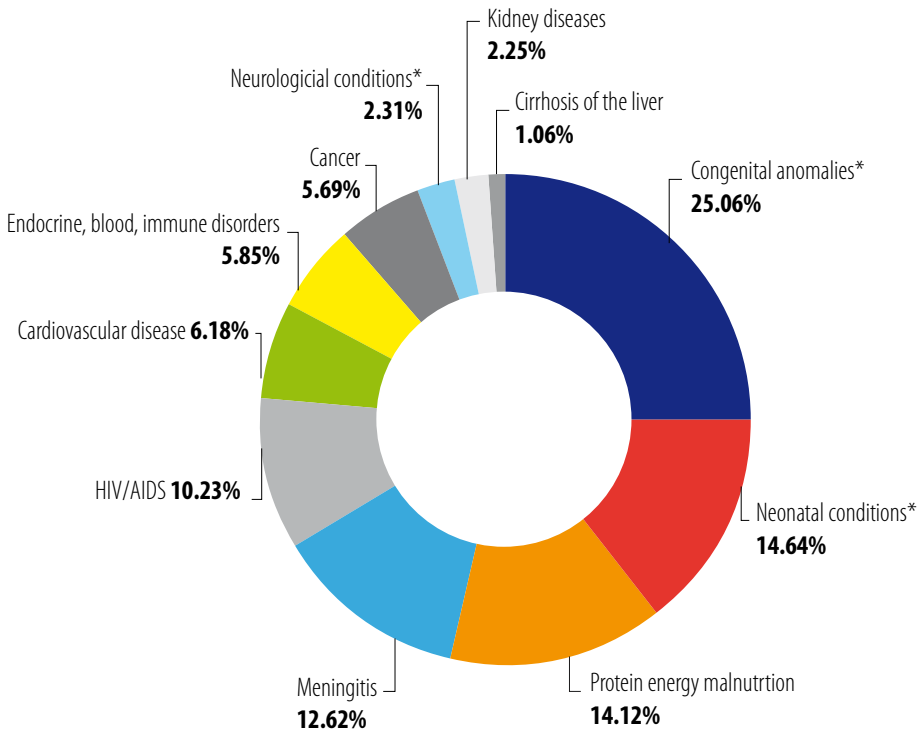
Access to PPC lags far behind that of adult services. Development of PPC is hampered by a number of factors including geography, lack of education, lack of public awareness, stigma and lack of consensus on the diseases and conditions appropriate for PPC. There is resistance to admitting that children need palliative care because it is emotionally difficult to admit that children suffer and die. Further, many myths persist about caring for seriously ill children, including a belief that children are not aware of their condition and do not experience pain in the same way as adults.

Estimates of the need for PPC are hampered by a lack of registries and reliable data collection from most countries. Need is unevenly distributed globally with almost half the need in sub-Saharan Africa and 98% of the need in LMICs. Children needing palliative care are not concentrated in any one area in a country and are difficult to serve after leaving institutions. Clinicians trained in PPC are few and far between, and children suffering from pain or other symptoms in an area without a trained clinician are likely to have inadequate relief or none at all.

Estimating the global need for PPC

Several estimates of the global need for PPC have been undertaken in recent years *(2,3,38)*. One estimate identified 11 categories of conditions that generate a need for PPC at the end of life only and the percentage of the need due to each condition (Figure 1).

Figure 1. Conditions that generate a need for palliative care at the end of life by disease group



*see excluded conditions (Appendix 6)

N = 1,170.011

Source: Reprinted with permission from Connor et al. 2014 *(38)*.

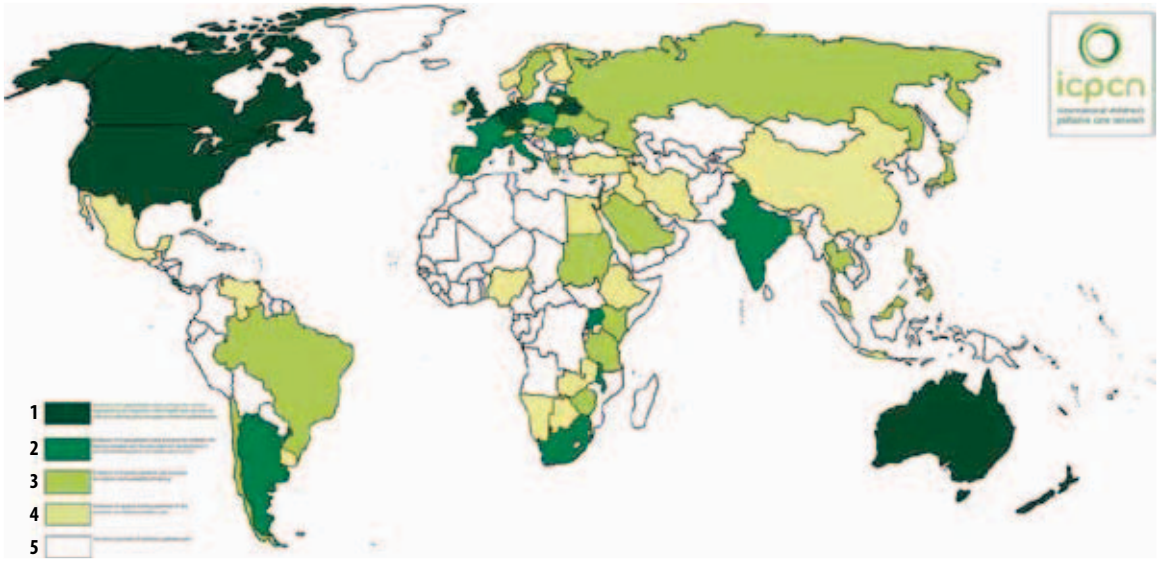
The total number of children in need of PPC globally each year may be as high as 21 million, and of these, 8 million may have problems that require specialist PPC *(2)*.

Local need for PPC can be estimated with assistance from key informants and the affected people. Direct stakeholders should be involved both in estimating the need and in the planning process for service implementation. A working group on PPC sanctioned by a ministry of health could examine local and international data and key informant information to estimate the probable range of need, from the lowest to the highest. Local mortality and disease prevalence data can be used, but these data are often unreliable or unavailable in LMICs.

Mapping levels of palliative care development

In addition to understanding the need for children's palliative care, it is also important to assess the capacity to provide PPC globally. Mapping of levels of PPC development was undertaken by the International Children's Palliative Care Network (ICPCN) using a five-level schema (Figure 2) *(29)*.

Figure 2. Levels of PPC development in 2015



Source: Reprinted with permission from Downing et al. 2016 (*29*).

1. Evidence (from figure 2) of broad palliative care provision for children. Approaching full integration within health care services as well as a national policy to support children's palliative care.
2. Evidence of broad palliative care provision for children with training available and focused plans for development of services and integration into health care services.
3. Evidence of localized palliative care provision for children and availability of training.
4. Evidence of capacity building activities for the provision of children's palliative care.
5. No known provision of children's palliative care.

Measurement of need for, and capacity to deliver, PPC are necessary elements in planning PPC in a country or region. This is usually done by knowledgeable individuals (including a national palliative care association if there is one) and can be done sequentially. In most LMICs, there are few PPC programmes, and these few may be known to key informants. The primary information needed is the capacity of these institutions to deliver PPC including:

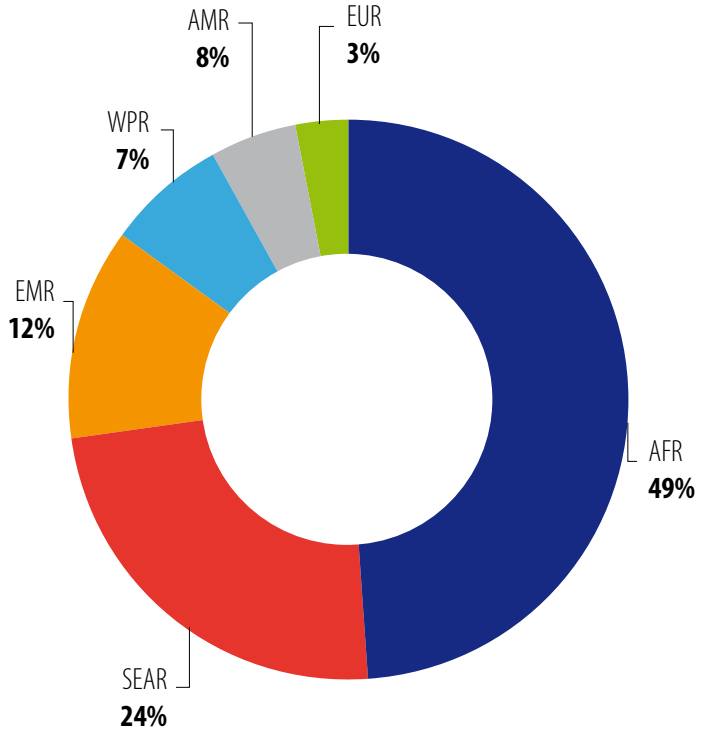
- number of patients who received care in one year
- diagnoses
- length of service by diagnosis and overall
- average daily census.

Surveys can be used to collect these data with follow-up of non-respondents. Once the need for PPC has been estimated and capacity assessed, it is then possible to conduct a gap analysis *(38)*. Gap analysis is essential for health care planning purposes as it shows the size of the unmet need for PPC.

Disparity in access to palliative care

Currently, 98% of the need for PPC is in LMICs, and nearly 50% of the need is in the African region (Figures 3 and 4). Yet few clinicians in LMICs have any training in PPC.

Figure 3. Distribution of children in need of palliative care by WHO region

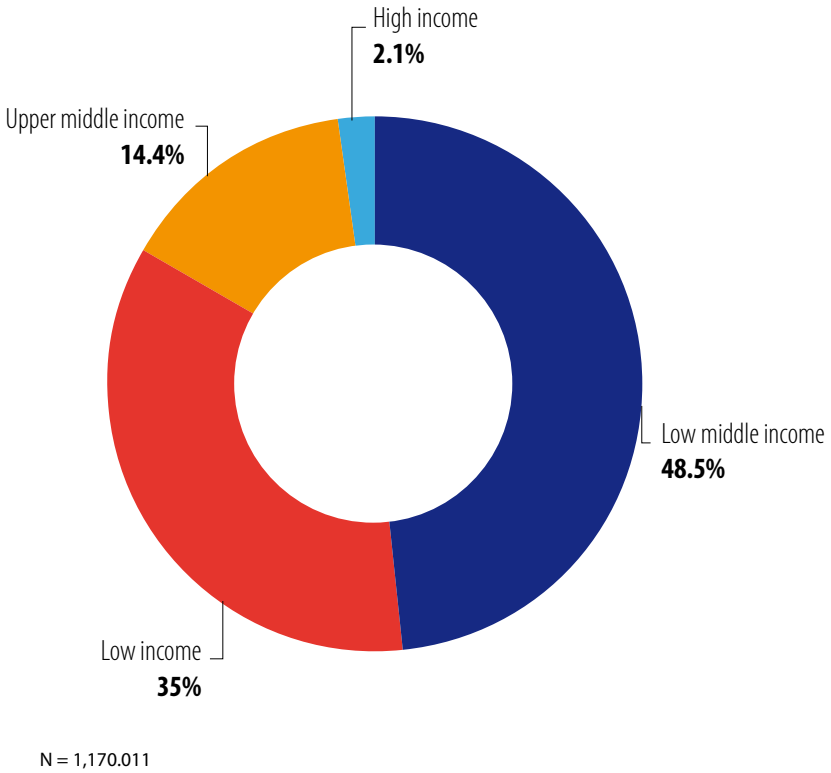


N = 1,170.011

AFR: African Region; AMR: Region of the Americas; SEAR: South-East Asia Region; EUR: European Region; EMR: Eastern Mediterranean Region; WPR: Western Pacific Region

Source: Connor et al. 2014 *(38)*.

Figure 4. Distribution of children in need of palliative care at the end of life by World Bank country income group



Source: Connor et al. 2014 *(38)*.

Programmes in PPC

An accurate estimate of the number of PPC programmes worldwide is not available at present. However, a number of centres of excellence have been identified that can serve as models for development:

- Members of ICPCN: http://www.icpcn.org/members-directory/
- All 196 members of the United Kingdom association Together for Short Lives: https://www2.togetherforshortlives.org.uk/portal/public/volunteer/List.aspx
- Members of the United States National Hospice and Palliative Care Organization that have paediatric palliative care services: https://www.nhpco.org/find-hospice

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3 Palliative care and symptom relief as part of comprehensive paediatric care

Generalist PPC

Most children suffering from problems associated with serious or life-threatening health conditions do not need a PPC specialist. Most PPC can be provided very well by generalist clinicians with basic- or intermediate-level training in palliative care, just as most infections can be competently treated by generalist clinicians and do not require intervention by an infectious disease specialist. Thus, health systems should require that general paediatricians, general practitioners, family doctors and paediatric nurse practitioners have at least basic training in PPC, and health system policies should make PPC one of the official responsibilities of these clinicians (Annex 5). All palliative care training programmes in LMICs, whether basic, intermediate or specialist, should address the special problems and needs of paediatric patients and their families at least until there are adequate numbers of paediatric clinicians trained in palliative care. Thus, any clinician trained in palliative care should be able to provide at least basic palliative care to children.

There are many similarities between general paediatrics and PPC that should facilitate integration of palliative care training into paediatrics training and practice. These include:

- emphasis on continuity of care and development of a trusting therapeutic relationship;
- integrated bio-psycho-social care;
- attention both to the patient and to the family; and
- special attention to patients' and family members' anxieties about both illness and treatment.

The emotional discomfort of contemplating the death of children can be a barrier to integration of PPC into general paediatrics. For the sake of patients and families, this barrier must be recognized and overcome.

Most patients in need of palliative care, whether adults or children, are at home. Generalist clinicians with palliative care training are essential to making palliative home care possible. First-level (district) hospitals should establish a palliative care and pain control clinic staffed by clinicians with basic or intermediate-level palliative care training. Their roles would include (see also Chapter 5):

- ongoing outpatient assessment of symptoms and adjustment of symptom control regimens to enable patients to stay at home;
- inpatient care for patients whose symptoms cannot be adequately controlled outside the hospital but who do not require higher-level care;
- referral of patients with severe or refractory symptoms to higher-level hospitals; and
- training and supervision of clinicians providing palliative care at community health centres (CHCs).

In settings where clinicians at the community level are not permitted to prescribe opioids for outpatients, physicians at the district level should take on this role for any patients in the district who require opioid therapy for pain or terminal dyspnea. Clinicians who provide palliative care at community CHCs – which may include doctors, clinical officers, assistant doctors, nurse practitioners or nurses with advanced palliative care training – should have basic training in palliative care (Annex 5).

Their roles should include (Chapter 5) *(22,39)*:

- ongoing outpatient assessment of symptoms and adjustment of symptom control regimens to enable patients to stay at home; ideally, at least one clinician at a CHC should be able to prescribe oral morphine for outpatients;
- training and supervision of community health workers (CHWs) who visit patients at home as often as daily to recognize uncontrolled symptoms or social or spiritual distress and report it to the CHC; and
- if possible, to provide inpatient hospice or end-of-life care for a maximum of one or two patients at a time whose symptoms are well controlled but whose families are unable to care for them at home.

PPC provision by physician-specialists in disciplines other than palliative care

Specialist doctors who frequently care for children with serious or life-threatening conditions, such as oncologists, cardiologists, intensivists and neonatologists, should be required to receive intermediate-level training in PPC (Chapter 5, Part 3). Health system policies should require that these physicians have PPC as one of their official responsibilities. Specialist physicians trained in this way, usually based at second-level (provincial) or third-level (regional referral) hospitals, will be able to respond adequately to most of the suffering of children that cannot be adequately relieved at the district or community level by generalist clinicians. In addition, these physicians will be capable of integrating palliative care with the curative and disease-modifying treatment for children that they usually practise. Training in palliative care also will prepare them to recognize when curative or life-sustaining treatment are likely to be more harmful than beneficial and to advise patients and families on the relative benefits and burdens of potential interventions. Health system policies also should require that second- and third-level hospitals have a palliative care interdisciplinary team (IDT) and that specialist physicians with intermediate-level training in palliative care be affiliated with the IDT. Basic palliative care training for generalist clinicians should include curriculum on when and how to refer patients to the IDTs at higher-level hospitals.

Specialist PPC

Some children have refractory or complex symptoms that even physicians with intermediate-level PPC training may be unable to relieve. These patients require intervention by palliative care specialist physicians who lead palliative care IDTs. However, there are as yet few palliative care specialists in LMICs, even fewer PPC specialist physicians and no PPC specialist training programmes. Palliative care specialist training programmes should be created as soon as possible in LMICs, and ministries of health should recognize palliative medicine as an official medical specialty to enable these programmes to develop and their graduates to practise. Palliative care specialist training programmes should include training in PPC for all trainees, and they should aim to develop a PPC specialist training track as soon as possible. National health care policies should require major children's hospitals to establish PPC services directed by PPC specialist physicians within a specified period of time.

PPC specialist physicians and IDTs are especially important in paediatric cancer centres. The majority of distressing symptoms in children with advanced cancer, such as pain, dyspnea and nausea/vomiting, are treated inadequately or not at all, even in HICs *(40–44)*. Further, new targeted cancer therapies and immunotherapies sometimes exacerbate symptoms, generate new ones or create complex clinical dilemmas for which palliative care expertise may be crucial. Similarly, hospitals that offer extra-corporeal membrane oxygenation (ECMO) or other invasive life-sustaining treatments should also offer palliative care provided by palliative care specialist physicians and IDTs to minimize the discomfort of critical care, to offer an alternative to life-sustaining treatment of questionable benefit and to ensure the comfort of children for whom life-sustaining treatment will be withdrawn.

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4 Essential Package of Paediatric Palliative Care and Symptom Relief

The Essential Package of Paediatric Palliative Care and Symptom Relief is the minimum palliative care and symptom relief that should be accessible by any child in any setting. The EP Ped is based on the essential package of palliative care described by Krakauer et al. *(22)* and Knaul et al. *(3)*, and adapted for children based on the expert opinions of the members of the WHO working group on PPC. It consists of a set of safe, effective, inexpensive, off-patent and widely available medicines, simple and inexpensive equipment, and basic social supports, which together can prevent and relieve suffering of all types – physical, psychological, social and spiritual (Table 5). It also includes the human resources needed to apply them appropriately, effectively and safely and to accompany patients and families throughout the course of the illness.

Medicines

The list of medicines in the EP Ped is based on the WHO Model List of Essential Medicines for Children *(45)* and adapted for this document. Medicines were selected based on the following criteria:

- they are necessary to prevent or relieve the specific symptoms or types of suffering most common in children with serious, complex or life-threatening health problems;
- the safe prescription or administration requires a level of professional competency achievable by doctors, clinical officers, assistant doctors or nurse anaesthetists with basic training in palliative care; and
- within its class of medicines, they offer the best balance between accessibility on the world market, clinical effectiveness, safety, ease of use and low cost.

Morphine and other opioids

Morphine, in oral fast-acting and injectable preparations, is the most clinically important of the essential palliative care medicines *(45)*. 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 first-line treatment for chronic pain outside of cancer, palliative and end-of-life care, except under special circumstances and with strict monitoring *(46)*. Morphine, in both injectable and oral fast-acting formulations, should be accessible by prescription at every referral, provincial and district hospital, and oral fast-acting morphine should be accessible by prescription at CHCs unless there is a serious and unavoidable risk of diversion of controlled medicines from CHCs. All doctors who ever care for patients with moderate or severe pain of the types described, or for patients with terminal dyspnea, 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 at prescribing morphine can be trained adequately with the curriculum in basic PPC described in this document or with similar curricula (Annex 5). Doctors also should be enabled to prescribe an adequate supply of morphine so that obtaining refills is feasible for 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 some countries, it may be possible for specially trained nurses to provide opioid therapy safely and effectively.

Table 5. EP Ped: interventions, medicines, equipment, human resources and social supports

Interventions	Inputs			
	Social supports	Medicines[a]	Equipment	Human resources[b]
Prevention and relief of pain or other physical suffering,[d] 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 (>8 years old) Furosemide, oral and injectable Haloperidol, oral and injectable Hyoscine butylbromide, oral and injectable Ibuprofen (naproxen, diclofenac, or meloxicam), oral (>3 months old) Lactulose (sorbitol or polyethylene glycol), oral Loperamide, oral Metaclopramide, oral and injectable (>1 month old) Metronidazole, oral, to be crushed for topical use Morphine, oral immediate release and injectable Naloxone, injectable Omeprazole, oral Ondansetron, oral and injectable[f] (>1 month old) 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) Diapers (baby and adult) 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,[e] 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	Diapers (baby and adult) or cotton and plastic	Doctors (with basic palliative care training) Nurses (with basic palliative care training) Social workers, psychologists, or grief counsellors CHWs (if available)
Prevention and relief of social suffering, acute or chronic	Income and in-kind support[c]			Social workers CHWs and/or volunteers (if available)
Prevention and relief of spiritual suffering				Local spiritual counsellors

[a] Based on WHO 2017 *(45)*. Acceptable alternative medicines are in parentheses: ( )

[b] Doctors may be paediatricians, general practitioners, family practitioners, surgeons, anaesthesiologists, intensivists, neonatologists, infectious disease specialists, palliative care specialists, clinical officers, or others. Nurses may include nurse-anaesthetists.

[c] 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).

[d] Other physical suffering includes breathlessness, weakness, nausea, vomiting, diarrhoea, constipation, pruritus, bleeding, wounds and fever.

[e] Psychological suffering includes anxiety, depressed mood, confusion or delirium, dementia and complicated grief.

[f] Only in hospitals that provide cancer chemotherapy or radiotherapy.

Sources: Knaul et al. 2017 *(3)*; Krakauer et al. 2018 *(22)*.

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 *(47)*. All hospitals, health centres and pharmacies should store morphine and other controlled medicines 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 and in local regulations on controlled medicines. Doctors should be trained to assess for 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' 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.

Non-opioid 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 in children older than eight years. Any doctor 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 Ped meets the following criteria. It is:

- necessary for the relief of at least one type of physical or psychological suffering;
- inexpensive, and
- simple to use with basic training.

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 safe-boxes for opioids (to be secured to a wall or immovable object); flashlights with rechargeable batteries (when no adequate light source is available for nocturnal home care); and baby and adult diapers or cotton and plastic bags to make 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 Ped does not include materials needed for palliative care that should be standard equipment for any health centre 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 service delivery site and on the competency in PPC 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 and bereavement support *(48–51)*.

Nurse-anaesthetists trained in basic palliative care and nurse practitioners with advanced palliative care training also may be able to provide these services in some settings. Nurses at CHCs can have a crucial role in supervising CHWs who provide palliative care, in providing palliative care that does not entail prescribing medicines and in triaging patients who may require attention from a doctor.

Midwives can have a crucial role in providing palliative care for critically ill neonates and emotional support for the parents. Their ability to prescribe medicines depends on their level of training and on local licensing laws. However, they can be trained to recognize moderate or severe distress in neonates and to transport patients in need of palliative care to the nearest health centre or other facility capable of providing it.

Clinicians trained in basic PPC occasionally may encounter physical or psychological suffering for which they feel incapable of providing adequate treatment, and referral for specialized PPC may not be possible in some settings. Examples may include pain refractory to high-dose morphine, depression refractory to maximum dose SSRI or psychotic disorders. However, if referral for appropriate specialist care is not possible, then a clinician with palliative care training should use whatever resources are available, including a palliative care hotline or other type of 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 and families frequently at home and by helping them to navigate the local health care system. With as little as three to six hours of training in palliative care, existing 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 health centre (Annex 5). In this way, they can accompany patients in need of palliative care and their families and help to assure their comfort by serving as the eyes and ears of their clinicians. Based on reports by 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 return to the hospital or health centre. 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, often also have work and other child-care responsibilities, and often live in poverty.

Clinicians should routinely ask patients with serious or life-limiting health problems or their families 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. This support should include, as appropriate, basic food packages, cash payments for housing or school fees, 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. These social supports help 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 appropriate burial can be a major financial burden for families, and inability to provide a funeral can become a chronic emotional burden.

Augmenting the EP Ped

The EP Ped includes only the minimum set of basic medicines, equipment, social supports and human resources that should be accessible by all patients and families in need. It should not be considered sufficient to meet all palliative care or symptom relief needs. Depending on the budget of humanitarian response organizations and the type of health emergency or crisis, the EP Ped may be augmented in various ways.

Medicines and other treatments:

- paediatric (liquid) formulations of paracetamol, ibuprofen, morphine and diazepam;
- topical lidocaine or other local anaesthetic ointment: for preventing pain from procedures;
- fentanyl, injectable: for preventing pain from brief procedures or dressing changes and for intravenous analgesia in patients with renal failure;
- 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;
- midazolam, injectable: for moderate sedation prior to painful procedures and for palliative sedation for intractable distress of a dying patient;
- hydrogel, topical: for dressing healable wounds; and
- access to palliative cancer treatments (radiotherapy, chemotherapy): for patients with incurable cancers.

Equipment:

- wheelchairs and canes: to improve mobility and reduce burden for family caregivers.

Human resources:

- palliative care specialist physician: for patients with particularly complex symptom control problems;
- child life specialist: to help children cope with illness, disability or loss of family members; and
- physical therapist: for injured patients and patients with disabilities.

Interventions for specific patient populations

Dying patients

In some cases, it is difficult to discern when a child is dying. For patients who may still benefit from disease-modifying or life-sustaining treatment, every effort should be made to obtain this treatment in combination with palliative care. When life-sustaining treatment is deemed more harmful than beneficial for a patient, or when it is no longer desired by the patient and family, it is essential that the patient not be abandoned but rather receive comfort-oriented treatment to prevent and relieve suffering and maximize quality of life. Failure to provide this service is medically and ethically indefensible.

The child should be placed in as quiet and private a location as possible and provision made for the family to be present. The prognostic understanding of the patient or family should be gently explored and corrected as needed and as culturally appropriate. Bad news should be conveyed in a manner appropriate for patient's developmental stage and for the patient's and family's culture and history. It should be made clear that there is never an intention to hasten death but that every effort can be made to ensure comfort at all times. Intensive efforts must be made to relieve pain and other symptoms. Comfort-oriented care sometimes requires an intensity and ingenuity that rivals critical care. In addition, patients and family members should have access to psychological first aid, defined by WHO as a "humane, supportive response to a fellow human being who is suffering and who may need support. It entails basic, non-intrusive pragmatic care with a focus on listening but not forcing talk, assessing needs and concerns, ensuring that basic needs are met, encouraging social support from significant others and protecting from further harm" *(52)*. Any doctor should be prepared and permitted to provide non-specialized psychological care that includes psychological first aid and prescription of psychotropic medicines for priority, uncomplicated mental health conditions. Comprehensive WHO guidelines on training non-specialized providers (e.g. doctors, nurses) in the assessment, management and referral of priority mental health conditions are available and should be included in palliative care training curricula (Annex 5) *(53)*.

For bereaved adults and children who do not have a mental disorder, it is recommended to follow general principles of care such as communication, mobilizing and providing social support and attention to overall well-being, to offer psychological first aid and encourage and facilitate participation in culturally appropriate mourning practices *(52,53)*. Bereavement support groups led by adequately trained personnel may be helpful *(54)*. Some interventions can be provided safely and effectively by CHWs with basic training *(51)*. Volunteer spiritual supporters should be sought to provide culturally appropriate spiritual support if requested by the patient or family.

Protein energy malnutrition

Efforts to rescue severely malnourished children should be combined with palliative care to maximize their comfort and to provide psychosocial support for the family. Treatment of adverse effects of re-feeding, such as vomiting and diarrhoea, may not only provide comfort, but also improve survival. The pain or dyspnea of dying children should be relieved and their parents emotionally supported.

Neonates

Neonates and babies have the highest death rate in the paediatric population. All preverbal children are vulnerable because of their inability to communicate their suffering. However, critically ill neonates are particularly vulnerable because, in many places, neonatal intensive care units offer only life-sustaining treatment and no palliative care. The two are not mutually exclusive: critical care and palliative care can and should be integrated to maximize the comfort of patients who may survive, and that of their parents. In HICs, palliative care is recommended for neonates born at extremely low birth weight (less than 0.5

kilograms) and those born before 23 weeks of gestation. In settings where state-of-the-art neonatal intensive care is not accessible, babies born after longer gestation or at higher birth weight may not survive and should receive palliative care. In any setting, palliative care:

- should be provided for children born with a life-limiting abnormality or malformation;
- should be initiated immediately for family support when a life-limiting abnormality or malformation is discovered during pregnancy or at birth and in case of a stillbirth (psychological, social and spiritual support);
- should be integrated with intensive illness-modifying or life-sustaining treatments for critically ill neonates;
- should be the only type of care when intensive illness-modifying or life-sustaining treatments will be more burdensome than beneficial and therefore will be withheld or withdrawn;
- should assist with decision-making about benefits and burdens of intensive illness-modifying or life-sustaining treatments for critically ill neonates; and
- should make bereavement support accessible as needed after a stillbirth or the death of any neonate or child.

When a life-limiting fetal anomaly is diagnosed during pregnancy, or when a stillbirth occurs, a midwife or traditional birth attendant can play an important role in providing palliative care. They can provide emotional support and advise the parents on:

- spending time with their dying baby, or holding a stillborn baby;
- making photographs or handprints and footprints that can become cherished memories and assist the bereavement process; and
- organizing baptisms, wakes or other rituals.

Obstetrical, neonatal and palliative care policies and procedures should guide the palliative care roles of midwives and traditional birth attendants. They should receive basic training in PPC and be welcomed as members of palliative care teams.

5 Implementing PPC and symptom relief

Part 1. Integrating PPC into health care systems and structures

WHO recommends a public health strategy for integrating palliative care into health care systems in a cost-effective manner to reach all in need *(4,55).* Inclusion of palliative care in national health care policies is crucial. Without policies that mandate palliative care services, it is unlikely that PPC will become widely accessible or sustainable. In general, the first steps towards integration of PPC into health care systems should be:

- a national palliative care policy that requires access for all – specifically including children – 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 PPC in any national policies or strategic plans on cancer, noncommunicable diseases (NCDs), paediatrics, HIV/AIDS, drug-resistant tuberculosis or primary health care (PHC).

Once such policies and strategic plans are in place, efforts can focus on ensuring accessibility of all essential medicines and equipment, including oral fast-acting and injectable morphine, and on training (Chapter 6). During these efforts, PPC training programmes should be developed. However, if policies do not precede training, most trainees may be unable to practise PPC and may not 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 children 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 children with serious or life-threatening health problems;
- basic palliative care training for practising nurses; and
- integration of basic training in palliative care, including PPC, into undergraduate medical, nursing and pharmacy training.

Next, or simultaneous with essential medicine procurement and training, PPC 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 PPC 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 PPC 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 and specialty hospitals);
- first-level (district) hospitals;
- CHCs; and
- home care.

A basic plan for integrating palliative care in general and PPC in particular into health care systems is described in Table 6. This plan can be used for palliative care policies. In LMICs, serious or life-threatening health conditions typically are diagnosed at second- and third-level hospitals, and treatment usually is

initiated there. Thus, palliative care services should be accessible in these institutions to provide initial symptom control, to maintain symptom control during treatment and to prepare a plan to keep the patient comfortable after discharge to a lower-level facility or to home. When treatment at a second- and third-level hospital is not needed or not appropriate and when the patient's symptoms are not complex or refractory to treatment, palliative care can be initiated and home care plans made at a first-level hospital. In most cases, home care services based at the patient's local CHC should be able to provide follow-up care after the patient's symptoms have been controlled and a palliative care plan made at higher level. In rare cases of severe refractory suffering, a patient may require end-of-life inpatient care at a first-, second- or third-level hospital. Examples include non-viable premature neonates with respiratory failure or patients with severe, refractory pain due to end-stage cancer. In cases where the patient's symptoms can be well-controlled but where the family lacks the ability to care adequately for the patient at home, the CHC should offer inpatient end-of-life care to a maximum of one or two patients at a time. In most cases, however, the patient should be able to remain at home with follow-up surveillance by a CHW and follow-up care as needed in the home, at the CHC or at the palliative care outpatient clinic of the district (first-level) hospital. It is crucial the national health care policies specify the types of palliative care services that must be implemented at each level of health care systems and also specify the training that each type of palliative care provider should have at each level.

Table 6. Palliative care interventions, delivery platforms and providers

Intervention	Delivery platform			
	Mobile outreach/ home care	CHC	First-level (district) hospitals	Second- and third-level (provincial, regional, specialty) hospitals
Ongoing care for patients with well-controlled symptoms related to serious or life-limiting health problems	■ CHWs provide surveillance and emotional support as often as daily ■ Visits as needed by nurse, doctor or social worker from the CHC with basic training in palliative care	■ Nurse and possibly also a doctor or social worker with basic training in palliative care provide outpatient care and possibly home visits as needed ■ Inpatient hospice care in some cases if the family is unable to provide adequate care at home	■ Small palliative care team including one or two part-time doctors with basic or intermediate training in palliative care ■ Inpatient hospice care if the family is unable to provide adequate care at home and if no inpatient care is available at CHCs ■ Outpatient palliative care clinic	

Initial control of moderate or severe symptoms related to serious, complex or life-limiting health problems Control of refractory suffering			■ Small palliative care team including one or two part-time doctors with basic or intermediate training in palliative care ■ Inpatient palliative care ■ Outpatient palliative care clinic	■ Palliative care team consisting of full- or part-time doctors with intermediate training in palliative care ■ Ideally, a palliative care specialist physician should lead the team at major cancer centres and general hospitals ■ Inpatient palliative care ward ■ Outpatient palliative care clinic

Source: Adapted from Krakauer et al. 2018 *(22)*.

The recommended transfer patterns for patients in need of palliative care are outlined in Figure 5. In general, patients whose health conditions already have been diagnosed and who need palliative care are referred only to the next higher or lower level as appropriate. However, there are several exceptions to this rule:

- Patients at second- or third-level hospitals whose symptoms have been well controlled and who wish to return home for palliative home care should be transferred directly to home and the case information transmitted to the local CHC in charge of home care.
- Patients who are at home or who are seen at a CHC and found to have severe, complex or refractory suffering that cannot be adequately relieved in the community may be transferred directly to a first-level hospital. However, if the patient already is known at a second- or third-level hospital, then the patient may be transferred directly to that hospital. In all instances, case information should be transmitted to the receiving hospital.
- In settings where an inpatient hospice exists, patients may be transferred there from any level of the health care system, and case information should be transmitted.
- In settings where a sub-acute care facility or nursing home is available, patients with uncomplicated health problems and well-controlled symptoms may be transferred there from any level of the health care system, and case information should be transmitted.

It is crucial that palliative care providers at each level of the health care system be able to communicate easily and reliably with providers at any other level at all times. For example:

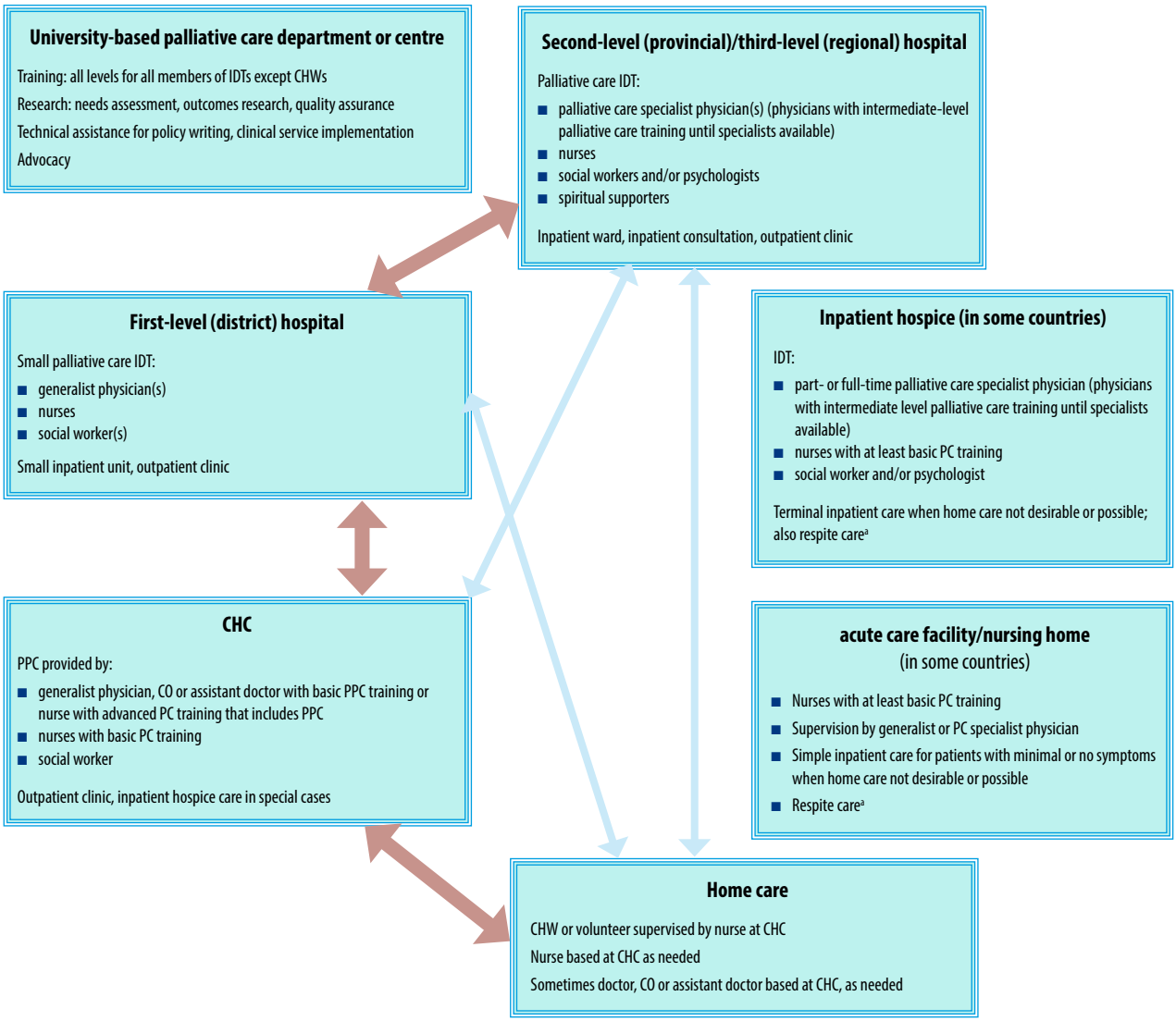
- a CHW must be able to reach a nurse or supervisor at the CHC quickly at any time to report a problem with a patient;
- a provider at a CHC must be able to reach a supervisor at the district level quickly at any time for advice on a complicated case; and

- a provider at a third-level hospital must be able to reach the appropriate person at a CHC to provide information about a patient who will be sent home for home palliative care.

Typically, this communication will be by mobile phone. Texting usually is inadequate to convey important clinical information. For LMICs with inadequate established referral systems, a standardized palliative care handover form that records the patient's clinical and social history, including disease-modifying and palliative treatments, key family members and caregivers, and any agreed-upon goals of care, is very conducive to optimum care. Budgets for palliative care should include funding for telecommunications and printing of such forms as well as for transportation for CHC staff members to visit patients at home as needed.

It also is crucial that palliative care training of all levels be integrated into the health care education system in each country or region for all types of palliative care providers, including physicians, clinical officers, assistant doctors, nurse practitioners, midwives, nurses, pharmacists and social workers. Typically, this training should be offered by a university that has a medical school, nursing school, pharmacy school and social worker school, but sometimes the training may be offered in separate schools for different professions. Creation of a department of palliative care or palliative care training centres at universities are encouraged (Figure 5).

Figure 5. Referral patterns for patients in need of palliative care



CHC, community health centre; CHW, community health worker; CO, clinical officer; IDT, interdisciplinary team; PC, palliative care; PPC, paediatric palliative care

[a] Temporary inpatient care that provides a respite from caregiving for the family.

Part 2. Models of palliative care delivery

Within the general plan for integrating palliative care into health care systems described in Part 1 of this chapter, various models will be necessary to fit the structure of the health care system in a given country and the strategic plans of the country's MOH, and to assure that all patients in need of palliative care will have access to it (Table 7). For example:

- in some settings, a home care model that entails mobile palliative care teams based at district or community levels and frequent telephone check-ins with the patient or family by telephone may supplant a model that relies on CHWs; and
- in some hospitals, a strong and active palliative care consultation service that works closely with link nurses in each ward with basic palliative care training may obviate the need for an inpatient palliative care ward (Textbox 2).

Table 7. Models of palliative care delivery

Location	Services
Home care	By staff members of a CHC with or without CHWs: ■ Family members, friends or community volunteers provide most care with support from CHWs or volunteers who visit frequently and report to a nurse at the CHC ■ A nurse (and sometimes also a doctor) from the CHC visits as needed and/or at regular intervals ■ A visiting nurse may be able to deliver medicines in some settings ■ A nurse with advanced training or a doctor may be able to prescribe an opioid during a home visit By a mobile team: ■ A team typically consisting at least of a doctor and nurse visits at regular intervals and when called by the patient or family. ■ In some settings, team members may be able to prescribe and/or deliver medicines including opioids
Outpatient clinic	Palliative care clinics may be based at CHCs or at hospitals of any level The clinic at a CHC would handle only simple palliative care problems, while the most complex problems should be addressed at the clinic of a third-level hospital where the most highly trained palliative care clinicians should work Clinics at all hospitals should have clinicians able to prescribe morphine for outpatients, and all hospitals pharmacies should stock oral fast-acting and injectable morphine
Inpatient care – hospital	Consultation model: Physicians trained in palliative care provide advice to the patient's responsible physician who then decides how to implement the advice Inpatient unit model: A room or ward devoted entirely to palliative care and staffed only by physicians and nurses trained in palliative care
Inpatient care – hospice	A house, hospital or hospital ward devoted entirely to end-of-life care and staffed by an IDT that includes physicians and nurses trained in palliative care
Day care	A location staffed by a nurse and CHWs or volunteers where patients receiving palliative care who are able to walk or travel by wheelchair can spend the day under supervision to enable family members to work or have respite time

Box 2. Inpatient palliative care services at Mulago National Referral Hospital, Uganda

At Mulago National Referral Hospital in Uganda, a palliative care link nurse programme was established. Nurses throughout the hospital, in both adult and paediatric units, were trained to provide basic palliative care and to refer patients with complex needs to the hospital's specialist palliative care team. As a result, the number of patients receiving palliative care increased dramatically. The majority (86%) required only basic palliative care from a link nurse, and 14% were referred for specialist palliative care. This programme demonstrated integration of palliative care into generalist services, ensured that generalist palliative care provision was accessible to all in need throughout the hospital and reached a far greater number of patients than could be seen by the specialist team alone. It also ensured that those receiving specialist care were those with the greatest complexity of need *(56)*.

Part 3. Training in palliative care and symptom relief

The 2014 World Health Assembly resolution WHA67.19 on palliative care urges each Member State to integrate into its health care education system three levels of palliative care training (Annex 4) *(4)*:

1. Basic training and continuing education in 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.

2. Intermediate training in palliative care 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.

3. 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.

Basic training in palliative care of approximately 35 hours should be included in all curricula of medical schools and nursing schools (Annex 5). The training may be offered either as a discrete course in the last year of medical or nursing school or integrated into other courses throughout the curriculum. For example, training on pain can be integrated into a course on the nervous system, and training on patient–clinician communication can be integrated into courses on psychiatry or medical ethics. The training should include both classroom and bedside teaching. Basic palliative care training also should be provided for all primary care clinicians unless their responsibilities preclude contact with patients in need of palliative care.

Intermediate-level palliative care training, lasting approximately 70 hours, should be integrated into specialist training curricula in all fields that entail treating patients with serious or life-threatening illnesses. In addition to paediatrics, oncology, infectious diseases, geriatrics and internal medicine, these include haematology, critical care, family medicine, tuberculosis, hepatology, neurology, cardiology, pulmonology, nephrology, neonatology, traumatology, anaesthesiology and surgery. The training should consist of both classroom teaching and hands-on, supervised clinical experiences. Specialists in these fields, who work mainly in hospitals, should be prepared to provide direct palliative care to their patients. In addition, the physicians who work full- or part-time on hospital-based palliative care teams should have at least intermediate-level palliative care training.

As soon as possible, palliative care IDTs at second- and third-level hospitals should be led by palliative care specialist physicians. Thus, LMICs should work to develop palliative care specialist training programmes that can supply palliative care specialist physicians for their country or region. Specialist training programmes should last at least one year but will vary according to each country's postgraduate medical training regulations.

Although it is best if clinicians providing PPC are fully trained in paediatrics and provide care only for children, generalist clinicians such as general practitioners, family doctors and primary care nurses can and should be trained and competent to provide PPC whenever paediatric specialists are not needed or not available. Basic and intermediate-level palliative care training aims not at specialization but rather at essential competencies *(57)*. General domains of competency in palliative care include:

- principles of palliative care
- communication
- optimizing comfort and quality of life
- care planning and collaborative practice
- loss, grief and bereavement
- professional and ethical practice in the context of palliative care
- professional resilience.

Essential competencies in PPC are described in Table 8. Generalists providing PPC should be able to obtain advice by telephone at any time from a paediatrician with intermediate-level palliative care training or a palliative care specialist physician. Such task shifting and task sharing is especially crucial in rural areas.

Table 8. Essential competencies in PPC

Key competency	Key components
Paediatric symptom assessment (pain and non-pain)	Use age-specific methods to assess symptoms such as pain, nausea, dyspnea, anxiety, depression, etc.
Appropriate medication selection, dosing and administration	Implement age and weight-based dosing with attentiveness to paediatric metabolism and excretion Use non-opioid, opioid and adjuvant therapies aligned with WHO principles; include appropriate use of scheduled along with as-needed doses for breakthrough pain Create/disseminate pharmacologic and non-pharmacologic treatment plan to include emergency plan; place emergency medications in the home with training for caregivers Refer to higher level for more specialized palliative care when needed
Psychosocial assessment and intervention (patient and family)	Identify and address the child's and family's illness understanding, fears and concerns, including those of siblings Assure child and family they will not be abandoned Identify child's and family's coping and communication styles and adjust care plan accordingly Communicate with child in a developmentally appropriate fashion Gently explore previous experiences with death, dying, other traumatic life events or special issues such as substance abuse or suicidal ideation, and adjust care plan to minimize further psychosocial stress Use play therapy such as music, storybooks, art for expression, reflection and distraction. Recognize impact of child's illness on larger community (faith groups, school, etc.) – offer to family to help communicate with school or community agencies Assess family's resources for bereavement support; make bereavement follow-up plan as needed

Disease trajectory recognition	Consider how manifestations and trajectory of disease may differ from adults and between children of different ages Provide developmentally appropriate anticipatory guidance regarding physical changes and symptom burden to decrease child's fear of the unknown
Developmentally informed and context-appropriate communication	Explore child and family emotions and behaviours Use play, art or storytelling to explore child's experience Truth-tell in a manner appropriate to patient's development, clinical situation and context Recognize that children grieve, worry about their family members and fear burdening their family members
Decision-making and advance care planning	Include the patient in decision-making as appropriate for the patient's values, culture and developmental stage Adjust care plan according to culture, coping and communication styles Honour relevant ethical principles, cultural norms and legal guidelines as appropriate Identify key decision-makers and provide information as necessary
Spiritual concerns as part of care	Consider referral to an appropriate spiritual care provider Offer to assist in explaining child's illness to spiritual provider, with permission Allow time for reflection on life meaning and purpose
Goals of care	Determine whether the goal of care is cure, maintenance of current level of health, comfort, or mixed When the goals of care preclude intensive life-sustaining treatment, write orders to protect the patient from cardiopulmonary resuscitation or other interventions inconsistent with the goal of care Develop care plan with the patient and/or family that integrates awareness of patient symptoms and disease trajectory with desires and goals of patient and family Provide guidance on best location of care (home, hospital, hospice) to achieve agreed-upon goals of care
Support tangible needs	Offer and arrange as much assistance as may be needed and as possible such as: ■ medical equipment (wheelchair, cane, suction, commode, hospital bed for the home) ■ social supports (food packages, cash transfers for rent or school tuition, transportation vouchers, in-kind support) ■ community services (visits from CHWs, nurses, mobile palliative care teams)

Source: Himelstein et al. 2004 *(58).*

Various curricula in PPC are available and may be adapted for use in any country (Table 9). Care should be taken when adapting a curriculum from an HIC to ensure it is as relevant as possible to the local clinical and cultural situation. For example, it should discuss only medicines in the EP Ped and those that are accessible or may soon become accessible in the country.

Table 9. Paediatric palliative care (PPC) curricula

Education in Palliative and End-of-life Care (EPEC – Pediatrics)
Developed for the United States and HICs. The curriculum consists of 19 online distance-learning modules and 5 in-person face-to-face conference sessions. http://bioethics.northwestern.edu/programs/epec/curricula/pediatrics.html
International Children's Palliative Care Network (ICPCN) e-learning programme
Developed in South Africa, intended for both professionals and lay people who participate in palliative care for children. A clinical site where children's palliative care is being practised is required so that the learner can undertake the clinical assessment which forms part of the course. http://www.icpcn.org/icpcns-elearning-programme/
End-of-Life Nursing Education Consortium-Pediatric Palliative Care (ELNEC-PPC)
Developed for the United States and HICs. Adapted from the ELNEC-Core curriculum to meet the needs of children and their families. The 10 modules include perinatal and neonatal content. http://www.aacnnursing.org/ELNEC/About
Harvard Medical School Center for Palliative Care, Global Program, Pediatric Palliative Care Curriculum for Low-resource Settings
Developed for Viet Nam and LMICs. Can be downloaded and adapted to local clinical and cultural situations. http://www.massgeneral.org/palliativecare/education/international_program.aspx

Given that most care for children with serious or life-threatening health conditions is provided by family members and at home, basic, patient-specific training should be provided to family caregivers. The training should be provided by a nurse from the local CHC or from a mobile palliative care team. It may include medicine administration, wound care, safe feeding, infection control, avoiding burn-out, and when and how to request help. Materials for training family caregivers also are available (Table 10).

Table 10. Training materials for family caregivers

Institute of Palliative Medicine (Calicut, Kerala, India) Palliative care: a workbook for carers
Developed for India and other LMICs. http://www.instituteofpalliativemedicine.org/downloads/Palliative%20Care%20Workbook%20for%20Carers.pdf
Home-based Palliative Care Training and Support Package for Young Children in Southern Africa
Developed in South Africa, a training and support package to guide home and community-based care workers to help caregivers of seriously ill young children at home in Southern Africa. Contact: snaicker@hsrc.ac.za

6 Ensuring access to essential medicines

Strong opioids such as morphine are essential for the treatment of pain caused by cancer, HIV/AIDS and other serious illnesses and due to traumatic injuries, burns and surgery. Yet despite being included on the WHO Model List of Essential Medicines for both adults and children, 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 *(45,59)*. 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 International Narcotics Control Board (INCB), have acknowledged that their emphasis historically has been on restricting opioid misuse and abuse, rather than on ensuring the medical availability of opioids *(60)*. Yet the United Nation's 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 *(61)*. This dual obligation of governments is called the principle of balance, a principle that has been affirmed by WHO *(62,63)*, 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 the reducing the risk of misuse and abuse and not at all on making these medicines available.

Examples of overly restrictive regulations include *(64)*:

- 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;
- restricting opioids to inpatients or to patients receiving hospice services;
- limits on opioid dose;
- limits on opioid prescriptions and dispensing to less than a 30-day supply when risk of diversion is minimal; and
- restricting family practitioners and general practitioners from prescribing them.

All health systems establish a system to monitor the flow of opioids from import or manufacture to use by the patient *(65)*. 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 stock-outs and other supply chain failures result in patients suffering both from opioid withdrawal symptoms and from pain and can increase the risk of illicit opioid use and suicide too *(66)*.

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 the following year and for the INCB to officially allocate the amount needed *(67)*. 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 and symptom relief can strengthen health care systems and promote UHC

Improved quality of life

Palliative care has been associated with improved patient outcomes, with financial risk protection for patients and their families and with reduced costs for health care systems *(3)*. Improved patient outcomes include better control of pain and other symptoms, decreased spiritual distress, enhanced quality of life, improved patient and family satisfaction, and reduced number of physician office visits, emergency department visits, hospitalizations and days in the intensive care unit at the end of life *(68,69)*. These improvements tend to be greatest when palliative care is initiated early in the course of illness *(69)*. In some cases, provision of palliative care has been associated with prolonged survival *(70)*. Less data are available on outcomes of palliative care for children than for adults. However, PPC has been associated with improvements in health-related quality of life, emotional well-being and family satisfaction *(40,43,71)*. Thus, evidence indicates that integration of palliative care enables health care systems to better achieve their mission of improving the well-being of those they serve.

Improved treatment outcomes

Palliative care should not be considered only as an alternative to curative or life-sustaining treatments of dubious benefit, but also as an essential complement to curative or disease-modifying treatments for serious or life-threatening health conditions. Adherence to curative or disease-modifying treatments can be difficult when symptoms of the disease or adverse effects of the treatment are not prevented or adequately relieved. Thus, palliative care may improve adherence particularly to toxic treatments such as those for drug-resistant tuberculosis and many cancers *(72)*. Among the global poor, poverty and other social problems also commonly make adherence difficult. In LMICs, treatment abandonment – the failure to start or complete medically indicated curative therapy – is a major cause of therapeutic failure in potentially curable childhood cancers *(73)*. Specific reasons for treatment abandonment have been found to include financial difficulties as well as distress caused by side-effects and by poor relationships with health care workers *(74)*. PPC could ameliorate all of these problems. Social supports such as those described in Chapter 4 also have been shown to reduce treatment abandonment and improve a patient's ability to adhere to treatment *(74–76)*. Thus, palliative care not only can improve patients' comfort, but also strengthen the ability of health care systems to effectively treat their serious and life-threatening conditions.

Lower costs for health care systems and financial risk protection for families

In many countries, patients and their families bear most of the burden of caring for patients with serious or life-threatening health problems. In addition to the often extreme emotional stress, families of medically ill children often experience profound social and economic burdens, including isolation, loss of income and catastrophic health care spending. Family caregivers, who usually are women or children, may be unable to work, go to school or participate in social activities because of the demands of caregiving. When patients go to the hospital in low-income settings, a family caregiver often must leave income-generating activities, school or caregiving for other children to accompany the patient. This puts patients' families at risk of financial ruin and caregivers at risk of exhaustion and health problems of their own *(22,77,78)*.

Multiple studies from HICs indicate that palliative care can reduce costs for patients and families, as well as for health systems *(79–83)*. Palliative care networks that include community-based care and home care, as described in Chapter 4 can enable patients to remain at home and comfortable rather than return to a hospital for symptom relief. They also may reduce demand for expensive disease-modifying treatments of dubious benefit near the end of life by providing a compassionate alternative and supportive counselling, and they can reduce the length of stay for patients already in the hospital by making symptom control accessible in the community. Families thereby are spared the costs of unnecessary admissions to the hospital, including transportation for the patient and caregiver to the hospital, hospital co-payments and lodging costs for the family caregiver. Because the family caregiver can remain at home and may be able to work at least part-time, there also may be less loss of income. Caregivers who are children may also be able to remain in school *(84–89)*.

Palliative care integration also can reduce costs for health care systems. As populations age, and as the prevalence of chronic NCDs rises, an increasing percentage of the health care budget is being spent on hospital inpatient care near the end of life that increasingly includes aggressive disease-modifying treatments or life-sustaining treatments of doubtful medical benefit *(86,90)*. Palliative care integrated into health care systems at all levels and including home care can reduce health care costs by decreasing unnecessary or non-beneficial resource utilization *(86)*. Rather than spending the last days, weeks or months of life in hospitals, patients can receive care at home or in the community that is less expensive and yields better outcomes. In addition, overcrowding in second- and third-level hospitals can be reduced. Thus, palliative care can help health care systems produce better results at lower cost *(22)*.

An additional benefit for health care systems and for public health can accrue from cost-effective palliative home care. CHWs, nurses from CHCs and mobile palliative care team members who visit patients at home can do more than palliative care. Home visits provide an opportunity for many other primary prevention and screening interventions, including:

- teaching about smoking cessation, indoor air quality, diet and exercise;
- encouraging prenatal care, childhood vaccinations, cervical cancer screening and HIV prevention and testing; and
- tuberculosis and cancer case-finding.

Thus, creating or enhancing home care capacity for palliative care also can strengthen capacity for disease prevention and early diagnosis. In addition, the communication links between each level of health care systems that are necessary for palliative care can be used to reduce loss to follow-up. Staff members of hospital-based services, such as cancer chemotherapy or specialist clinics, can inform CHCs of impending appointments, and CHWs can then remind patients and uncover any impediments to the patient's ability to keep the appointment in time for CHC staff to find a solution.

Promotion of UHC

In 2015, United Nations General Assembly resolution 70/1 established the Sustainable Development Goals (SDGs) *(91)*. SDG 3 aims to ensure healthy lives and promote well-being for all at all ages, and SDG 3.8 is about achieving UHC, 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. Palliative care exists to attend to, accompany and ensure the well-being of those with serious or life-threatening health problems whose health care needs exceed disease treatment. Thus, palliative care is essential to the achievement of SDG 3 and UHC. WHO specifically mentions palliative care in its definition of UHC: "The UHC means that all individuals and communities receive the health services they need without suffering financial hardship. It includes the full spectrum of essential, quality health services, from health promotion to prevention, treatment, rehabilitation and palliative care" *(92)*.

8 Research and quality improvement in paediatric palliative care

To develop high-quality, cost-effective palliative care services for children, research and quality improvement initiatives are much needed *(93–95)*. The 2014 World Health Assembly resolution WHA67.19 on palliative care asserts the importance of evidence-based palliative care (Annex 4) *(4)*. Likewise, WHO has called for research on evidence gaps identified during development of the WHO *Guidelines on the pharmacological treatment of persisting pain in children with medical illnesses (96,97)*. Currently, however, there is a dearth of evidence on PPC, especially from LMICs where the vast majority of patients in need are located.

There are a variety of significant barriers to research in palliative care in general, especially in LMICs *(29,94,98–100)*. These include:

- difficulty in identifying useful and researchable outcome measures;
- lack of research funding;
- absence of national and institutional research strategies;
- lack of a research infrastructure and culture in LMICs, including adequate and timely research ethics approval processes; and
- lack of research skills and overwhelming patient load in LMICs.

While all efforts are needed to reduce or eliminate all barriers, this chapter focuses on research priorities for PPC. A wide range of national and global priorities for research in PPC have been proposed, including studies of *(95, 101–104)*:

- palliative care needs of children in specific locations (situation analyses);
- relative effectiveness of interventions for pain and other symptoms *(95)*;
- clinical outcomes such as quality of life;
- effectiveness of training on palliative care-related knowledge and attitudes;
- existence and degree of implementation of palliative care policy;
- optimum models of care;
- trust in health care providers;
- ethical issues; and
- cost and cost-effectiveness of palliative care.

Palliative care needs assessment or situation analysis

To design palliative care services that provide optimum benefit for a specific population, the most common and most severe types of suffering must be known. When no such data exist on the target population, palliative care situation analyses should 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 *(105–107)*, or it may be an entire region or country *(108,109)*. The situation analysis may use multiple detailed surveys *(109)*, 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, because very young children are unable to participate in surveys, data must be obtained either from family members

or using validated tools for assessing symptoms in preverbal or linguistically impaired children *(110,111)*. Older children who are in severe discomfort or near the end of life often 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 *(112,113)*. 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 *(105)*.

Design of optimum palliative care services for a population also depends on understanding of common cultural and religious conceptions of illness, treatment and death, and of common attitudes towards health care providers and the health care system *(114–119)*. In addition, children's attitudes towards illness, treatment and death change along with their physical, emotional, psychological and spiritual development, and all people's attitudes are influenced by personal experience *(120)*. Thus, research is needed on trends in what children with serious or life-threatening illnesses and their families experience in specific geopolitical, cultural, religious and economic contexts. Attitudes of health care providers at all levels towards palliative care also warrants investigation. For example, irrational fear of prescribing opioids is common and commonly results in poor care and outcomes *(121)*. If such opiophobia is discovered, it can be addressed through education.

Optimum PPC treatments

There is a need for research to assess the effectiveness of palliative care treatments in general, and the need for such studies in children is even greater. Studies of the safety and relative effectiveness of palliative medicines in children are difficult for many reasons, including the relatively small number of potential research subjects, the inability of children to provide informed consent and the necessary ethical guidelines to protect vulnerable subjects in addition to the barriers to palliative care research cited above. However, WHO has proposed detailed and ranked priorities for research on medical management of persisting pain in children (Table 11).

Table 11. WHO priorities for research on pharmacologic treatment of persisting pain in children with medical illnesses

First group of priorities

- Assessment of two-step treatment strategy.
- Research on alternative strong opioids to morphine (comparative trials of opioids in terms of effectiveness, side-effects and feasibility of use).
- Research on intermediate potency opioid analgesics (e.g. tramadol).
- Long-term safety data concerning first-step medicines (ibuprofen/paracetamol).

Second group of priorities (neuropathic pain)

- Antidepressants, specifically tricyclic antidepressants and selective serotonin reuptake inhibitors and newer antidepressants of the class of serotonin and norepinephrine reuptake inhibitors for persisting neuropathic pain in children. Gabapentin for persisting neuropathic pain in children.
- Ketamine as an adjuvant to opioids for refractory neuropathic pain in paediatric patients with longterm medical illness.

Third group of priorities

- Randomized controlled trials (RCTs) on alternative routes to the oral route of opioid administration (including RCTs comparing subcutaneous and intravenous routes).

Fourth group of priorities

- Update Cochrane reviews on opioid switching including paediatric data, if available.
- Randomized controlled trials on opioid switching and research on dose conversion in different age groups.
- Randomized controlled trials on short-acting opioids for breakthrough pain in children.

Other areas for research and development

- Research and psychometric validation of observational behaviour measurement tools for persisting pain settings (neonates, infants, preverbal and cognitively impaired children).
- Prospective clinical trials to investigate opioid rotation protocols and their efficacy in preventing side-effects or opioid tolerance and dose escalation.
- Development of divisible, dispersible, oral solid-dosage forms of paracetamol and ibuprofen.
- Research into appropriate formulations for the extemporaneous preparation of oral liquid morphine. Dissemination of available evidence on the preparation of stable extemporaneous formulations.
- Child-appropriate oral solid dosage forms of opioid analgesics.
- Research on equianalgesic dosages in conversion of opioid analgesics for different age groups.

Source: WHO 2012 (97).

Ongoing data collection on PPC integration, accessibility, quality and outcomes

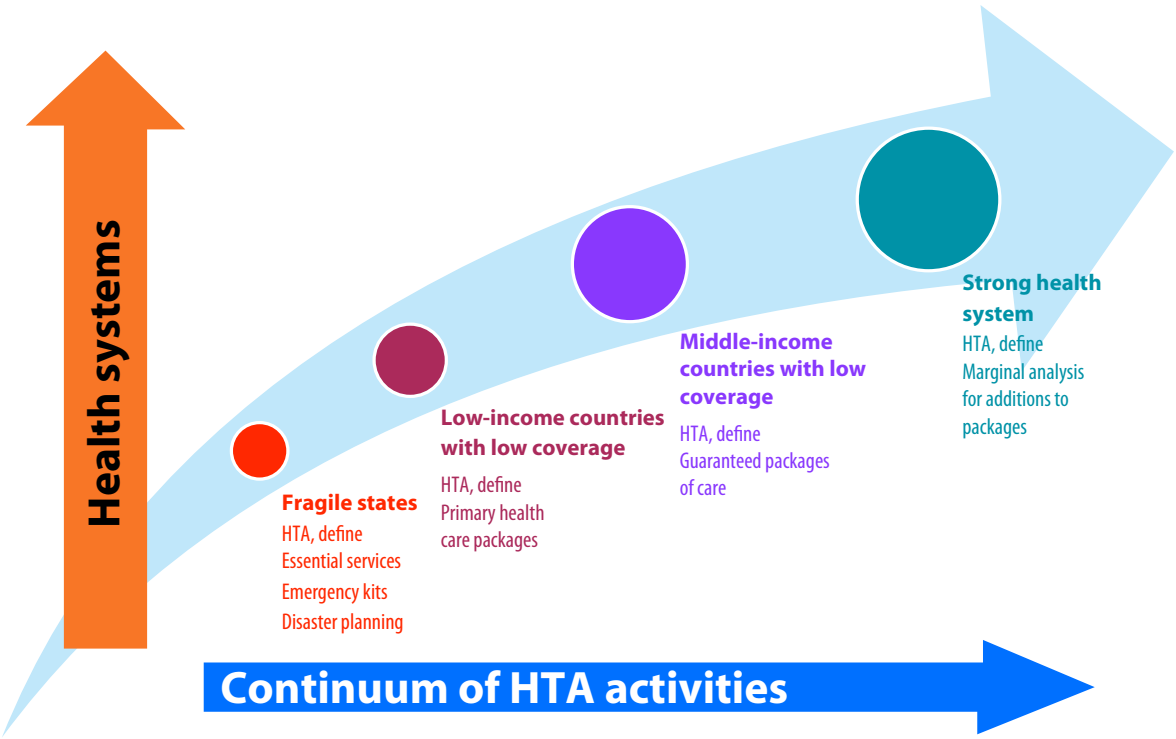
The degree of integration of PPC into a health care system, and its accessibility, may be assessed with a few output measures such as those developed by WHO for its periodic survey of NCD country capacity around the world *(122)*. Such a study might explore:

- whether government funding is provided for PPC;
- whether there is a national policy that includes PPC and whether a national policy on paediatrics includes palliative care;

- whether such policies are operational, under development or not in effect;
- whether oral morphine is available in over 50% of the inpatient and outpatient paediatric care facilities of the public health sector;
- whether palliative care is accessible by over 50% of paediatric patients in the public health system; and
- whether palliative home care is accessible by over 50% of paediatric patients in the public health system.

To periodically assess the quality and outcomes of PPC, the same instruments used for palliative care situation analyses can often be used. Where feasible, however, WHO endorses health technology assessments (HTA) to systematically evaluate the properties, effects and/or impacts of health interventions (Figure 6) *(123)*. 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 including 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 6. Health technology assessment: a tool to inform decision-makers in support of UHC



Source: WHO 2018 (124).

All providers of PPC, 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 12. These indicators are adapted from a previous WHO guide for planning managers *(7)*.

Table 12. Sample indicators for assessing enhanced access to palliative care in PHC

Type of indicator	Indicator	Unit of measure
Policy	Existence of a current national paediatrics strategy or plan that includes palliative care plan/programme	Yes/No
	Essential Package of Palliative Care for Paediatrics and Symptom Relief (EP Ped) 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? At the community level?	Yes/No Yes/No
Education	Proportion of medical schools that include paediatric palliative care education in undergraduate curricula	Ratio of medical schools with paediatric palliative care education at undergraduate level to total medical schools
	Proportion of nursing schools that include paediatric palliative care education in undergraduate curricula	Ratio of nursing schools with paediatric palliative care education at undergraduate level to total nursing schools
	Proportion of medical technical schools (for training clinical officers, assistant doctors, nurse practitioners, or feldshers) that include paediatric palliative care education in undergraduate curricula	Ratio of medical technical schools with paediatric palliative care education to total medical technical schools
Service provision	Inclusion of paediatric palliative care on the official list of services provided at the primary care level	Yes/No
	Number of communities that provide paediatric palliative care services	Ratio of number of communities that provide palliative care services to number of communities
Essential medicines	Consumption of strong opioids per cancer death	Average milligrams of oral morphine equivalents per number of deaths
	All WHO essential medicines for palliative care included on the national list of essential medicines	Yes/No
	Proportion of districts where oral morphine is available in primary health care	Ratio of districts with oral morphine available in primary care to total districts
Outcomes	Percentage of paediatric patients who had access to palliative care at the time of death	Percentage of deceased patients that had access to paediatric palliative care.

Sources: Adapted from WHO 2016 *(7)* and Knaul et al. 2017 *(3)*.

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Annexes

Annex 1

Convention on the Rights of the Child (excerpts)

Adopted and opened for signature, ratification and accession by United Nations General Assembly resolution 44/25 of 20 November 1989

Entry into force 2 September 1990

http://www.ohchr.org/Documents/ProfessionalInterest/crc.pdf

PART I

Article 3

1. In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration.
2. States Parties undertake to ensure the child such protection and care as is necessary for his or her well-being, taking into account the rights and duties of his or her parents, legal guardians, or other individuals legally responsible for him or her, and, to this end, shall take all appropriate legislative and administrative measures.
3. States Parties shall ensure that the institutions, services and facilities responsible for the care or protection of children shall conform with the standards established by competent authorities, particularly in the areas of safety, health, in the number and suitability of their staff, as well as competent supervision.

Article 23

1. States Parties recognize that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community.
2. States Parties recognize the right of the disabled child to special care and shall encourage and ensure the extension, subject to available resources, to the eligible child and those responsible for his or her care, of assistance for which application is made and which is appropriate to the child's condition and to the circumstances of the parents or others caring for the child.
3. Recognizing the special needs of a disabled child, assistance extended in accordance with paragraph 2 of the present article shall be provided free of charge, whenever possible, taking into account the financial resources of the parents or others caring for the child, and shall be designed to ensure that the disabled child has effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to the child's achieving the fullest possible social integration and individual development, including his or her cultural and spiritual development.
4. States Parties shall promote, in the spirit of international cooperation, the exchange of appropriate information in the field of preventive health care and of medical, psychological and functional treatment of disabled children, including dissemination of and access to information concerning

methods of rehabilitation, education and vocational services, with the aim of enabling States Parties to improve their capabilities and skills and to widen their experience in these areas. In this regard, particular account shall be taken of the needs of developing countries.

Article 24

1. States Parties recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. States Parties shall strive to ensure that no child is deprived of his or her right of access to such health care services.

2. States Parties shall pursue full implementation of this right and, in particular, shall take appropriate measures:
   (a) To diminish infant and child mortality;
   (b) To ensure the provision of necessary medical assistance and health care to all children with emphasis on the development of primary health care;
   (c) To combat disease and malnutrition, including within the framework of primary health care, through, inter alia, the application of readily available technology and through the provision of adequate nutritious foods and clean drinking-water, taking into consideration the dangers and risks of environmental pollution;
   (d) To ensure appropriate pre-natal and post-natal health care for mothers;
   (e) To ensure that all segments of society, in particular parents and children, are informed, have access to education and are supported in the use of basic knowledge of child health and nutrition, the advantages of breastfeeding, hygiene and environmental sanitation and the prevention of accidents;
   (f) To develop preventive health care, guidance for parents and family planning education and services.

3. States Parties shall take all effective and appropriate measures with a view to abolishing traditional practices prejudicial to the health of children.

4. States Parties undertake to promote and encourage international co-operation with a view to achieving progressively the full realization of the right recognized in the present article. In this regard, particular account shall be taken of the needs of developing countries.

Article 27

1. States Parties recognize the right of every child to a standard of living adequate for the child's physical, mental, spiritual, moral and social development.

2. The parent(s) or others responsible for the child have the primary responsibility to secure, within their abilities and financial capacities, the conditions of living necessary for the child's development.

3. States Parties, in accordance with national conditions and within their means, shall take appropriate measures to assist parents and others responsible for the child to implement this right and shall in case of need provide material assistance and support programmes, particularly with regard to nutrition, clothing and housing.

4. States Parties shall take all appropriate measures to secure the recovery of maintenance for the child from the parents or other persons having financial responsibility for the child, both within the State Party and from abroad. In particular, where the person having financial responsibility for the child lives in a State different from that of the child, States Parties shall promote the accession to international agreements or the conclusion of such agreements, as well as the making of other appropriate arrangements.

Annex 2

Seventieth World Health Assembly resolution WHA70.12 Cancer prevention and control in the context of an integrated approach (excerpts)

http://apps.who.int/gb/ebwha/pdf_files/WHA70/A70_R12-en.pdf

31 May 2017

The Seventieth World Health Assembly,

Having considered the report aware that early diagnosis and prompt and appropriate treatment, including pain relief and palliative care, can reduce mortality and improve the outcomes and quality of life of cancer patients; on cancer prevention and control in the context of an integrated approach; …

1. URGES Member States, taking into account their context and institutional and legal frameworks, as well as national priorities: …

(10) to develop and implement evidence-based protocols for cancer management, in children and adults, including palliative care;

(15) to provide pain relief and palliative care in line with resolution WHA67.19 (2014) on the strengthening of palliative care as a component of comprehensive care throughout the life course;

(17) to promote early detection of patients' needs and access to rehabilitation, including in relation to work, psychosocial and palliative care services;

(19) to continue fostering partnerships between government and civil society, building on the contribution of health-related nongovernmental organizations and patient organizations, to support, as appropriate, the provision of services for the prevention and control, treatment and care of cancer, including palliative care;

Annex 3

Child-friendly healthcare: a manual for health workers (excerpts)

Child Friendly Healthcare Initiative (CFHI)

http://www.cfhiuk.org/publications/cfhi_manual/cfhi_manual.pdf

Preface

This is an assessment and implementation manual about "Child Friendly Healthcare" (CFH) written for health workers who plan, organise, provide or give care to children and their families. The manual defines CFH by translating the articles of the United Nations Convention on the Rights of the Child (UNCRC) into simple CFH "Standards" that are applicable to everyday healthcare practices. It provides a method and process for assessing these and a simple structure for making any wanted or needed improvements so that children and their families everywhere can receive the "best possible" healthcare, regardless of circumstance.

The Child Friendly Healthcare Initiative (CFHI), a child health quality improvement program, was developed by Childhealth Advocacy International (CAI), Charity No: 1071486, in collaboration with The United Nations Children's Fund (UNICEF), The Child and Adolescent Department of Health and Development of the World Health Organisation (WHO), the Royal College of Paediatrics and Child Health (RCPCH), UK and the Royal College of Nursing (RCN), UK.

What is the "best possible" healthcare?

The practice of CFH Standards at their best possible level of practice.

The best possible:

- Considers the child's "best interests"
- Covers the preventive, investigative, curative and palliative aspects of health care taking into account the most up-to-date evidence-base for each care given
- Is affordable and effective
- Is appropriate, taking into account the resources (human and material) and technology available and the needs of other children sharing these
- Is child centred

STANDARD 7: Recognising and relieving pain and discomfort

'Health care providers, organisations and individual health workers, share a responsibility to advocate for children and to reduce the fear, anxiety and suffering of children and their families by ensuring that they recognise, assess and relieve the physical and psychological pain and discomfort of children.'

Supporting criteria

1. A separate pain and other symptom management/palliative care service/s with lead health professionals and/or multi-disciplinary team/s.

2. Systems of care, guidelines and job aides (for example tools to assess and relieve pain) to help with symptom recognition, symptom assessment and restraint for procedures.
3. Written guidelines, evidence based wherever possible, used by everyone to help with symptom relief, that include advice on the relief of different types of pain and other distressing symptoms (both physical and psychological), and on how to use non-pharmacological and pharmacological pain relieving strategies in the different ages groups:
4. Material resources including:
   - A safe, secure supply of free or affordable essential drugs for symptom relief that includes opiates and non-opiates;
   - Distraction toys and other resources to aid non-pharmacological pain and other symptom management.
5. The use of individual pain (and other symptom) plans made with the children and their parent/carer.
6. Psychosocial support for children, families and health workers.

Discussion

The pilot project found large numbers of children in the participating countries suffering from uncontrolled pain and other distressing symptoms, both physical and psychological.

Improved technology and potential advances in care do not always protect or improve the treatment of these distressing symptoms and can on occasion be an additional cause. Routine procedures (without pain relief), such as dressing wounds are frequent causes of unnecessary pain and suffering for a child. In some countries it is common for a child to be paralysed by drugs or partially sedated without concurrent and appropriate pain relief.

The State has a role to play in making it better for children by not restricting or blocking the availability of vital pain relieving drugs (including opiates) due to security concerns or outdated and mistaken beliefs about their appropriateness for use in children and misplaced concerns about risks of addiction.

In countries where opiates are available, there may be a reluctance to use them due to these misguided beliefs and also a lack of understanding about how to use them. Whilst it is upsetting for health workers when they are unable to help a distressed child, the effects on the child and their family are much worse and can only be imagined, especially if the child has a chronic illness, a terminal illness or any other life-limiting condition.

It is ethically wrong and a failure of a health professional's duty for a child to suffer from uncontrolled pain or other distressing symptoms. This is particularly the case for a child who has a permanent disability that is associated with chronic symptoms or one who cannot be cured of their illness and may be near the end of their life. Relieving pain and distressing symptoms is not always about cure, but is about making the experience of living "now" more bearable (that is improving the quality of remaining life).
Improved technology and potential advances in care do not always protect or improve the treatment of these distressing symptoms and can on occasion be an additional cause. Routine procedures (without pain relief), such as dressing wounds are frequent causes of unnecessary pain and suffering for a child. In some countries it is common for a child to be paralysed by drugs or partially sedated without concurrent and appropriate pain relief.

The State has a role to play in making it better for children by not restricting or blocking the availability of vital pain relieving drugs (including opiates) due to security concerns or outdated and mistaken beliefs about their appropriateness for use in children and misplaced concerns about risks of addiction.

Effective relief from pain and other distressing symptoms from birth to adulthood could be better if health workers:

- were more aware of the suffering and discomfort that all children may experience (including newborn babies) due to pain and other distressing symptoms;
- always anticipating a child's pain and other distressing symptoms;
- gave a higher priority to relieving each individual child's pain and other distressing symptoms;
- made greater use of pain and symptom relieving drugs, both non opiates and opiates;
- understood and used simple non-pharmaceutical methods that can help (supportive, cognitive, behavioural and physical);
- knew about and anticipated all the things that can make the experience of pain or other symptom worse.

To "make it better" best practice is for health workers to have core (during initial training) and regular education/training opportunities on the recognition, assessment and treatment of pain and other distressing symptoms. Best possible practice is also facilitated by having, whenever possible, separate skilled health professionals who lead and guide the treatment of pain and other symptoms. Having a multidisciplinary team dedicated to symptom relief and other aspects of palliative care, and using standardised guidelines for managing pain and other distressing symptoms, are known to be effective ways of improving care and sharing good practice.

The child's normal health worker working together with the child and their carers (who know the child best) can often reduce pain and other distressing symptoms by:

- planning each individual child's care as each child responds differently to pain and other distressing symptoms.
- anticipating pain and taking effective measures and/or giving drugs before the symptoms occur, for example before a procedure or operation. Children with recurrent distressing symptoms should not wait for these to re-occur before receiving relief.
- using pain/symptom assessment tools to help them recognise and assess a child's symptoms and guide the care they need.
- giving drugs in a way that does not cause more pain and distress. Drugs are often still given in a way that is painful for the child, for example by intramuscular injection. The same drugs are frequently available and equally effective as an intravenous or oral preparation, often at a lower cost.
- advocating for the child's needs to be met, if they are unable to meet these needs themselves.

Before using drugs, or where they are unavailable there is much that can be done to relieve suffering and make an unpleasant experience more bearable, such as:

- being honest with the child and preparing them for what might be a painful experience can help them to cope. Anxiety and mistrust of health workers will make the experience worse;
- using appropriate play, stimulation and distraction to help in the management of pain and other symptoms;
- using heat, cold, touch and other comfort measures as these can sometimes help the distress of pain and other symptoms;
- giving psychological support, simple kindness and involving parents and other familiar carers where possible.

Annex 4

Sixty-seventh World Health Assembly resolution WHA67.19 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;[1]

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

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

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

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

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

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

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,[4] 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;

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1 Document 67/31.

2 Document E/INCB/2010/1/Supp.1.

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

4 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:[5]

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,[6] on improving access to and rational use of pain management medicines, in line with the United Nations international drug control conventions;

[5] And, where applicable, regional economic integration organizations.

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

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;

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;[7]

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

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.

Annex 5

Sample curricula in paediatric palliative care

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

Day 1

1.1 Paediatric palliative care basic training course: goals and agenda

Slide presentation

1.2 Epidemiology of serious and life-threatening health problems among children in the country

Slide presentation

1.3 Paediatric palliative care: definition, principles, accessibility, and moral imperative

Slide presentation/large group discussion

1.4 Ethical issues and patient–doctor communication in paediatric palliative care

Slide presentation/large group discussion

1.5 Palliative care assessment in children

Slide presentation

1.6 Growth and development of children in need of palliative care

Slide presentation

1.7 Helping children cope in medical settings

Slide presentation/large group discussion

Day 2

2.1 Pain assessment and treatment in children

Slide presentation

2.2 Non-pharmacologic approaches to pain relief in children

Slide presentation

2.3 Preparing children for medical procedures

Slide presentation

2.4 Paediatric pain cases

Small group discussion

Day 3

3.1 Dyspnea assessment and treatment

Slide presentation/case discussion

3.2 Nausea/vomiting assessment and treatment

Slide presentation

3.3 Constipation/diarrhoea assessment and treatment

Slide presentation

3.4 Psychological distress in seriously ill children: depression, anxiety, insomnia

Slide presentation

3.5 Altered mental status: delirium in children

Slide presentation

Day 4

4.1 Talking with parents and children about serious illness

Presentation/large group discussion

4.2 Loss, grief and bereavement

Slide presentation/large group discussion

4.3 Psychosocial suffering and support

Slide presentation/large group discussion

4.4 Role play: Psychosocial support

Small group role play

4.5 Health care worker resilience and self-care

Short lecture and large group discussion

4.6 Memorial ceremony

Group activity

Day 5

5.1 Optimum use of life-sustaining treatment

Slide presentation/large group discussion

5.2 Complex medical and ethical issues in caring for a dying child

Large group case discussion

5.3 Current state of paediatric palliative care in the country

Slide presentation

5.4 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/diarrohea: 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, and 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. Community health workers' 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 a supportive ways

Presentation/discussion

5. Know how to recognize uncontrolled symptom.

Presentation/Q&A

6. Know 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: 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

A really practical handbook of children's palliative care: for doctors and nurses anywhere in the world

http://www.icpcn.org/a-really-practical-handbook-of-childrens-palliative-care/

African Palliative Care Association (APCA)

https://www.africanpalliativecare.org/

Asia Pacific Hospice Palliative Care Network

http://aphn.org/

Center to Advance Palliative Care. Pediatric palliative care field guide: a catalogue of resources, tools and training to promote PPC innovation, development, and growth

https://www.capc.org/topics/pediatric-palliative-care/

Children's Project on Palliative/Hospice Services (ChiPPS), a program of the National Hospice and Palliative Care Organization of the United States

https://www.nhpco.org/chipps-e-journal

End-of-life Nursing Education Consortium (ELNEC)

https://elnec.academy.reliaslearning.com/

European Association for Palliative Care (EAPC)

http://www.eapcnet.eu/

European Association of Palliative Care (EAPC) Primary Care Reference Group

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

ICPCN e-learning programme

http://www.icpcn.org/icpcns-elearning-programme/

International Association for Hospice and Palliative Care

https://hospicecare.com/home/

International Children's Palliative Care Network

http://www.icpcn.org/

Latin American Palliative Care Association

http://www.cuidadospaliativos.org/

NHPCO Standards of practice for pediatric palliative care and hospice

https://www.nhpco.org/childrenspediatricschipps/pediatrics-professional-resources

Pain and Policy Studies Group

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

Palliative care for infants, children and young people, the facts: a document for health care professionals and policy makers. Prepared by the EAPC Task Force on palliative Care for Children

http://www.eapcnet.eu/LinkClick.aspx?fileticket=DeiV2yhtOZA%3D

Palliative Care Guidelines Plus

http://book.pallcare.info/

Pediatric palliative care: recommendations for treatment of symptoms in the Netherlands

https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4634793/

Together for Short Lives: Basic Symptom Control in Paediatric Palliative Care

http://www.togetherforshortlives.org.uk/professionals/resources

When children die: improving palliative and end-of-life care for children and their families

https://www.nap.edu/catalog/10390/when-children-die-improving-palliative-and-end-of-life-care

WHO Guidelines on the pharmaceutical treatment of persisting pain in children with medical illness

http://www.who.int/medicines/areas/quality_safety/guide_perspainchild/en/

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/

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

  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.thewhpca.org/

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 persons grieving after the death of a loved one.

Capacity-building

A process by which individuals, institutions and societies develop abilities, individually and collectively, to perform functions, solve problems and set and achieve their goals.

Children

Persons up to their 18th birthday/the age of 18 years (United Nations).

Civil society

Structures independent from governments such as nongovernmental organizations (NGOs) and human rights groups, independent activists and human rights defenders, religious congregations, charities, universities, trade unions, legal associations, families and clans.

Community health workers (CHWs)

Persons who assist with health care in their own communities, are selected by the communities, should be answerable to the communities for their activities, should be supported by the health system but not necessarily a part of its organization, and have shorter training than professional workers.

Health

A state of complete physical, mental and social well-being and not merely the absence of disease or infirmity. (Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference, New York, 19–22 June, 1946; signed on 22 July 1946 by the representatives of 61 Member States [Official Records of the World Health Organization, No. 2, p. 100] and entered into force on 7 April 1948. The Definition has not been amended since 1948.)

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 near 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.

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.

Noncommunicable disease (NCD)

A disease or medical condition that is non-infectious and non-transmissible among people, such as heart disease, stroke, cancer, diabetes and chronic lung disease.

Nongovernmental organization (NGO)

An organized entity that is functionally independent of, and does not represent, a government or state.

People-centred health services

Health services that are 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.

Primary health care (PHC)

Essential health care based on practical, scientifically sound and socially acceptable methods and technology. It 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. It should be universally accessible to individuals and families in the community, and should be affordable for the community and country at every stage of their development

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 the SHS that is 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 the main cause of 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

World Health Organization

World Health Organization
20, Avenue Appia
1211 Geneva 27
Switzerland

http://www.who.int/servicedeliverysafety/en

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