

## Chapter 12

# Palliative Care and Pain Control

Eric L. Krakauer, Xiaoxiao Kwete, Stéphane Verguet, Hector Arreola-Ornelas, Afsan Bhadelia, Oscar Mendez, Natalia M. Rodriguez, Zipporah Ali, Silvia Allende, James F. Cleary, Stephen Connor, Kristen Danforth, Liliana de Lima, Liz Gwyther, Ednin Hamzah, Dean T. Jamison, Quach Thanh Khanh, Suresh Kumar, Emmanuel Luyirika, Anne Merriman, Egide Mpanumusingo, Diana Nevzorova, Christian Ntizimira, Hibah Osman, Pedro Perez-Cruz, M. R. Rajagopal, Lukas Radbruch, Dingle Spence, Mark Stoltenberg, Neo Tapela, David A. Watkins, and Felicia Knaul



## INTRODUCTION

Palliative care has been shown to provide significant and diverse benefits for patients with serious, complex, or life-limiting health problems. Such benefits include the following:

- Reduced physical, psychological, and spiritual suffering (Abernethy and others 2003; Gwyther and Krakauer 2011; Higginson and others 2014; Krakauer 2008; Singer and others 2016; Temel and others 2010; WHO 2008; Zimmerman and others 2014)
- Improved quality of life (Singer and others 2016; Zimmerman and others 2014)
- Prolonged survival in some situations (Connor and others 2007; Temel and others 2010).

Palliative care also can lower costs to health care systems (Chalkidou and others 2014; DesRosiers and others 2014; Gomez-Batiste and others 2012; Jamison

and others 2013; Knaul and others 2017; Summers 2016). For these reasons, it is recognized globally as an ethical responsibility of all health care systems and a necessary component of universal health coverage (World Health Assembly 2014). Yet palliative care is rarely accessible in low- and middle-income countries (LMICs). This chapter describes an essential package (EP) of palliative care services and treatments that could and should be accessible to everyone everywhere, as well as the sites or platforms where those services and treatments could be offered. Thus, it was necessary to make a preliminary estimate of the burden of health-related suffering requiring palliative care.

To roughly estimate the need for palliative care, we identified the serious, complex, or life-limiting conditions listed in the *International Classification of Diseases (ICD)-10* that most commonly result in physical, psychological, social, or spiritual suffering (WHO 2015a). We then estimated the types, prevalence, and duration of suffering resulting from each condition. On the basis

Felicia Knaul is senior author.

Corresponding author: Eric L. Krakauer, Harvard Medical School, Boston, Massachusetts, United States; eric\_krakauer@hms.harvard.edu.

of this characterization of the burden of suffering, we propose an EP of palliative care and pain control designed to do the following:

- Prevent or relieve the most common and severe suffering related to illness or injury.
- Be affordable, even in LMICs.
- Provide financial risk protection for patients and families by providing a realistic alternative to expensive, low-value treatment.

We costed the EP in one low-income country (Rwanda), one lower-middle-income country (Vietnam), and one upper-middle-income country (Mexico) and projected these costs for LMICs in general (Knaul and others 2017). At the conclusion of this chapter, we provide guidance on how to integrate the EP into health systems as an essential element of universal health coverage (UHC) in LMICs. We also discuss how to augment the EP as soon as is feasible to further prevent and relieve suffering.

This chapter draws directly on the work of the *Lancet* Commission on Global Access to Palliative Care and Pain Control (the *Lancet* Commission) (Knaul and others 2017).

## THE NEED FOR PALLIATIVE CARE

In 2015, there were 56 million deaths, including nearly 9 million from malignant neoplasms, more than 1 million from human immunodeficiency virus/acquired immune deficiency syndrome (HIV/AIDS), more than 17 million from cardiovascular diseases, and more than 3 million from chronic obstructive pulmonary disease (COPD) (WHO 2016). These and other serious, complex, or life-limiting health problems generate multiple kinds of suffering, typically categorized in the palliative care literature as follows (WHO 2002):

- Pain and other physical distress
- Psychological distress
- Social distress
- Spiritual distress.

Existing data, mostly from high-income countries (HICs), indicate that well over 50 percent of patients who die of malignant neoplasms and HIV/AIDS experience pain (Foley and others 2006). Pain is also common among those who die of heart disease, COPD, renal failure, neurologic disease, and dementia (Moens, Higginson, and Harding 2014; Solano, Gomes, and Higginson 2006). A recent meta-analysis of pain prevalence studies,

almost all from HICs, revealed that 75 percent of patients receiving anti-cancer treatment or with advanced, metastatic disease had pain, most of which was moderate or severe (Doyle and others 2017; Van den Beuken-van Everdingen, Hochstenbach, and Joosten 2016). Dyspnea—shortness of breath—is especially common among people who die of COPD and heart failure and only slightly less common among those who die of malignant neoplasms and HIV/AIDS (Moens, Higginson, and Harding 2014).

Depressed mood and anxiety are quite common among patients with a variety of advanced life-threatening illnesses. Data on prevalence of social and spiritual distress among these patients are scant. A study in the United States found that 44 percent of patients with advanced cancer experienced spiritual pain. In an impoverished rural district in Malawi, 76 percent of patients receiving palliative care needed social supports. In Germany, approximately 50 percent of patients receiving palliative care needed such supports (Hercé and others 2014; Ostgathe and others 2011).

The *Lancet* Commission on Global Access to Palliative Care and Pain Relief (Knaul and others 2017) identified (a) the 20 ICD-10 conditions that most commonly result in a need for palliative care and (b) the specific categories of suffering typically caused by each condition (table 12.1). Almost all of the identified conditions can cause any of the four categories of suffering. In addition, psychological and social distress can be a cause of at least some of the ICD-10 conditions (Farmer and others 2006). To determine the number of deaths per year from each condition, and hence gain insight into the need for palliative care, the Commission used mortality data from the WHO Global Health Estimates (GHE) for 2015 (Mathers and others 2018, chapter 4 of this volume) and aligned these data with the ICD-10 conditions using a conversion document from the WHO (2017). The Commission then estimated the percentage of people who die from each condition (“decedents”) who have health-related suffering that requires palliative care.

The Commission also identified the conditions that often lead to physical, psychological, social, or spiritual suffering, even among nondecedents, defined as people who do not die in a given year. These conditions include some that may be curable (drug-resistant tuberculosis and some malignancies), others that may be well controlled for long periods (HIV/AIDS and musculoskeletal disorders), and others from which patients may recover (serious injuries). It also was necessary to identify the specific types of suffering within each category (for example, pain, dyspnea, and nausea are types of physical suffering) and to estimate the prevalence and duration of each type.

**Table 12.1** Conditions Responsible for the Need for Palliative Care

Condition/disease	Decedents							
	Patients		Symptoms (%)					
	Rank	%	Total		Physical		Psychological	
			All symptoms		All symptoms		All symptoms	
Rank	%	Total days	At least days	Total days	At least days	Total days	At least days	
<i>a. LMICs</i>								
Malignant neoplasms	1	26	47	45	50	46	36	36
CVD	2	17	11	12	12	12	7	9
Lung disease	3	11	9	11	8	11	12	12
Injuries	4	6	0	1	0	1	1	1
TB	5	6	6	6	4	4	10	9
Premature birth and trauma	6	5	0	0	0	0	0	0
HIV	7	5	12	8	11	8	12	12
Liver disease	8	5	3	3	3	3	2	1
NI heart disease	9	4	3	3	3	3	4	4
Dementia	10	3	4	4	3	3	10	10
All other		11	5	8	5	8	6	6
All (millions)		20.6	9,143	2,473	7,191	2,378	1,952	1,054
<i>b. Global</i>								
Malignant neoplasms	1	30	51	49	54	51	39	39
CVD	2	16	10	10	11	11	6	8
Lung disease	3	11	8	10	7	10	11	11
Injuries	4	6	0	1	0	1	1	1
TB	5	5	4	5	3	3	8	7
Dementia	6	5	6	6	4	4	13	13
Liver disease	7	5	2	3	3	3	2	1
Premature birth and trauma	8	4	0	0	0	0	0	0
HIV	9	4	9	6	9	6	10	9
NI heart disease	10	4	3	3	3	3	3	4
All other		11	6	8	6	9	7	7
All (millions)		25.6	11,900	3,231	9,347	3,105	2,553	1,376

Source: Adapted with permission from Knaul and others 2017.

Note: CVD = cardiovascular disease; HIV = human immunodeficiency virus; LMICs = low- and middle-income countries; NI = non-ischemic; TB = tuberculosis.

a. The other illness conditions that commonly result in a need for palliative care are hemorrhagic fever, leukemia, dementia, inflammatory disease of the central nervous system, degeneration of the central nervous system; chronic ischemic heart disease, renal failure, congenital malformations, atherosclerosis, chronic musculoskeletal disorders, and malnutrition.

The Commission identified 20 conditions that account for 81 percent of global deaths and 80 percent of deaths in LMICs. Based on mortality figures for 2015 and our estimates, at least 50.5 million people each year with these conditions in LMICs, including decedents and nondecedents, require palliative care. Approximately 60 percent of these patients are nondecedents. More than 46 million

deaths occurred in LMICs in 2015; of these, about 20 million or 45 percent experienced health-related suffering that required palliative care. Patients in LMICs account for 17 billion days per year of need for palliative care—80 percent of the annual global total. Among decedents in LMICs, 10 conditions account for approximately 90 percent of patients and 95 percent of total days of

health-related suffering. The other 10 conditions each account for less than 3 percent of decedents and days with health-related suffering.

## THE GLOBAL SUFFERING DIVIDE: DISPARATE ACCESS TO PALLIATIVE CARE AND PAIN CONTROL

Despite compelling evidence of a huge burden of remediable health-related suffering and of the efficacy of palliative care and pain treatment, these essential health services are rarely accessible in LMICs. Data from the International Narcotics Control Board show that 91 percent of the morphine consumed worldwide in 2013 was consumed in HICs, which have only 19 percent of the world's population; people in LMICs, which account for 81 percent of the world's population, only consumed 9 percent (Pain and Policy Studies Group 2017). Given that morphine is essential to relieve moderate and severe pain (WHO 1996, 2012) and that morphine consumption is the most common—although imperfect—measure of palliative care accessibility, the data reveal an enormous disparity between rich and poor in meeting the need for palliative care.

Available data indicate that 74 percent of countries—virtually all of them LMICs—had at best isolated palliative care provision as of 2013 (Connor and Sepulveda Bermedo 2014). Among the 9 percent of countries where palliative care is “at a stage of advanced integration into mainstream service provision,” only Romania and Uganda are LMICs, and most people in need lack access to palliative care even in these two countries (Connor and Sepulveda Bermedo 2014, 39–40). The global suffering divide appears to be one of the world's largest health care inequities. The EP of palliative care that we propose is designed specifically to be the minimum acceptable package for the lowest income settings. Accordingly, although necessary for all countries, the EP is not exhaustive; palliative care can be improved by expanding the package to include additional medicines, equipment, and human resources.

## AN ESSENTIAL PACKAGE OF PALLIATIVE CARE AND PAIN CONTROL

Patients with life-threatening illnesses are the sole focus of palliative care according to the current WHO definition, and there are calls for it to be revised and expanded (Gwyther and Krakauer 2011; WHO 2002). There is large-scale, unrelieved health-related suffering among other groups as well. In particular, patients in LMICs

typically lack access to relief of pain and other types of suffering that result from common health problems that may be cured (drug-resistant tuberculosis and some malignancies) or controlled for a long period (HIV/AIDS and musculoskeletal disorders) or from which patients are likely to recover (serious injuries). The need for palliative care in low-resource settings is often determined by the magnitude of suffering, the inadequacy of existing capacity to respond, and the resultant need for relief. Therefore, the EP of palliative care and pain control that we propose should be as follows:

- Accessible at all levels of health care systems and in patients' homes.
- Adapted to local cultures, as well as clinical and social situations. For example, in resource-poor settings, the social circumstances of the patient and family members may be a major source of the patient's suffering and may need to be a focus for palliative care (Gwyther and Krakauer 2011).
- Integrated with disease prevention and treatment programs, although not considered a substitute for these, and assist patients in accessing and adhering to optimum disease treatment—if they desire such treatment and if it may be more beneficial than harmful according to patients' values, balanced with scientific evidence. Further, palliative care workers have a responsibility to advocate for access to comprehensive health care including, but not restricted to, disease-modifying treatments, such as cancer chemotherapy, antiretroviral treatment, or effective medicines for multidrug resistant tuberculosis (Gwyther and Krakauer 2011; Shulman and others 2014).
- Applied not only to persons who are dying but also to those living with long-term physical, psychological, social, or spiritual sequelae of serious, complex, or life-limiting illnesses or of their treatment. The EP should be applied to relieve acute pain and other acute symptoms when medically indicated.
- With adequate levels of palliative care training and skill, applied by health care workers of various kinds, including primary care providers, generalists, and specialists in many disciplines and from basic to intermediate to specialist.

### Design of the Essential Package

The EP that we propose is a key component of health systems and is designed to relieve the most common and severe suffering related to illness or injury, to be low cost and feasible to deliver in LMICs, and to protect patients and their families from catastrophic health expenditures (table 12.2). It consists of a list of

**Table 12.2** Delivery Platforms for the Essential Palliative Care Interventions

Intervention	Delivery platform			
	Intersectoral	Mobile outreach or home care	Health center (PHC)	First-, second-, and third-level hospitals
Control of chronic pain related to serious, complex, or life-limiting health problems	<ul style="list-style-type: none"> <li>Routine social assessment</li> <li>Income and in-kind support<sup>a</sup></li> </ul>	<ul style="list-style-type: none"> <li>Surveillance and emotional support by community health workers as often as needed (sometimes daily)</li> <li>Visits by PHC nurse or doctor as needed</li> </ul>	<ul style="list-style-type: none"> <li>Oral immediate-release morphine and other essential medicines and simple equipment for prevention and relief of chronic pain</li> </ul>	—
Control of other types of physical and psychological suffering <sup>b</sup> related to serious, complex, or life-limiting health problems	<ul style="list-style-type: none"> <li>Routine social assessment</li> <li>Income and in-kind support<sup>a</sup></li> </ul>	<ul style="list-style-type: none"> <li>Emotional support and suffering surveillance by community health workers as often as needed (sometimes daily)</li> <li>Visits by PHC nurse or doctor as needed</li> </ul>	<ul style="list-style-type: none"> <li>Essential medicines and simple equipment for prevention and relief of other types of physical and psychological suffering</li> <li>Psychological counseling</li> </ul>	—
Control of refractory suffering (chronic pain, other types of physical and psychological suffering <sup>b</sup> that have not or cannot be controlled at lower level)	<ul style="list-style-type: none"> <li>Routine social assessment</li> <li>Income and in-kind support<sup>a</sup></li> </ul>	—	—	<ul style="list-style-type: none"> <li>Oral immediate-release morphine and injectable morphine and other essential medicines and simple equipment for prevention and relief of chronic pain and other types of physical and psychological suffering<sup>c</sup></li> <li>Psychological counseling<sup>c</sup></li> </ul>
Acute pain related to surgery or serious injury	—	—	—	<ul style="list-style-type: none"> <li>Essential medicines and simple equipment for prevention and relief of acute pain<sup>c</sup></li> </ul>

Note: PHC = public health care. — = this type of care not provided in this setting.

a. Support provided only for patients living in extreme poverty and for one caregiver per patient.

b. Physical suffering includes breathlessness, fatigue, weakness, nausea, vomiting, diarrhea, constipation, pruritus, bleeding, and wounds. Psychological suffering includes anxiety or worry, depressed mood, confusion or delirium, and dementia.

c. Care devolves to lower level once effective treatment is established.

medicines, based on the WHO Model List of Essential Medicines for Palliative Care (WHO 2015b, 2015c). Centrally important in this list is immediate-release morphine. The EP includes equipment (lock boxes) and procedures to assure against misuse of opioids. The package also includes some small and inexpensive equipment. In addition, the package specifies several types of palliative care interventions and the platform or health care system level at which each intervention and each item in the package should be available. Finally, the package includes intersectoral inputs in the form of income and in-kind support required by any patient or family caregiver living in extreme poverty. (See annex table 12A.1 for an exhaustive list of medicines and other inputs required for the EP.)

### Medicines

Morphine, in oral immediate-release and injectable preparations, is the most **clinically important** of the essential palliative care medicines (WHO 2011). 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. We do not recommend the use of opioids for chronic pain outside of cancer, palliative, and end-of-life care, except under special circumstances and with strict monitoring (Dowell, Haegerich, and Chou 2016). All physicians who ever care for patients with moderate or severe pain of the types described, or for patients with terminal dyspnea, should be able to prescribe oral and injectable morphine for inpatients and outpatients in any dose necessary to provide adequate relief as determined by the patients. Physicians should be able to prescribe an adequate supply of morphine so that obtaining refills is feasible for patients or families without requiring unreasonably frequent, expensive, or arduous travel.

Although ensuring access to morphine for anyone in need is imperative, it also is necessary to take reasonable precautions to prevent diversion and nonmedical use. Model guidelines for this purpose are available (Joranson, Maurer, and Mwangi-Powell 2010). Oral immediate release and injectable morphine should be accessible at all third-, second, and first-level hospitals. Personnel at health centers also should be trained in opioid analgesia and safe storage so that morphine may be safely dispensed by prescription in these settings as well.

Among the other essential palliative medicines are oral and injectable haloperidol and oral fluoxetine or another selective serotonin reuptake inhibitor (SSRI). Although these medicines are considered psychiatric or psychotropic medicines, they have multiple

essential uses in palliative care and are safe and easy to prescribe. For example, haloperidol is the first-line medicine in many cases for relief of nausea, vomiting, agitation, delirium, and anxiety. An SSRI, such as fluoxetine, is the first-line pharmacotherapy for depressed mood or persistent anxiety, both of which are common among patients with serious, complex, or life-limiting health problems. All physicians at any level of the health care system and who care for patients with these symptoms should be trained and permitted to prescribe these medicines—not solely psychiatrists or neurologists.

### Equipment

The EP includes equipment that often is needed for palliative care yet may not be available in all health centers and hospitals in LMICs. Such equipment includes pressure-reducing mattresses, adult diapers, opioid lock boxes nasogastric tubes, and urinary catheters (annex table 12A.1). For the sake of efficiency, the EP does not include materials needed for palliative care that should be standard equipment for any health center or hospital, such as gauze and tape for dressing wounds, nonsterile examination gloves, syringes, and angiocatheters.

### Psychological and Spiritual Counseling

Interventions to relieve psychological distress may be provided not only by psychologists but also by adequately trained and supervised physicians, nurses, or social workers at any level of the health care system (Belkin and others 2011; Patel 2014; Rahman and others 2016). For patients or family members with complicated psychological problems, such as suicidality, psychotic disorders, or bipolar disorder, referral should be made to psychiatrists, if possible. In addition, hospital-based staff members should routinely ask patients with serious, complex, or life-limiting health problems if they desire spiritual counseling, and hospitals should allow local volunteer spiritual counselors to visit inpatients upon request by the patient or family.

### Social Supports

Social supports should be accessible both for any patient in need of palliative care and for their main caregiver in instances of extreme poverty. Given that extreme poverty is both a cause and an effect of serious, complex, or life-limiting health problems, it is crucial that meaningful social supports are accessible (Bamberger 2016). Such social supports include transportation vouchers, cash payments, food packages, and other types of in-kind support (annex table 12A.1) (Carrillo and others 2011; Syed, Gerber, and Sharp 2013). In most cases, funding for these social supports should come not from health care

budgets but from antipoverty or social welfare programs. Thus, to be able to implement all aspects of the full EP, there must be intersectoral coordination.

### Human Resources

The EP should include adequate time for trained personnel at each level of the health care system to provide palliative care consisting of the interventions, medicines, equipment, counseling, and social supports described earlier. These personnel include doctors, nurses, counselors such as social workers or psychologists, pharmacists, community health workers, and family caregivers (annex table 12A.1). Community health workers require a minimum of several hours of training to prepare them to recognize and report any uncontrolled suffering to a supervisor. Capable family caregivers should be trained, equipped, and encouraged by staff at health centers to provide basic nursing care such as wound and mouth care and medicine administration. Nurses and doctors at health centers who provide palliative care or who instruct family caregivers need basic training and all doctors who care for patients with serious, complex, or life-limiting health problems at hospitals require intermediate training. Ideally, all countries should have palliative care specialist physicians to lead training and service implementation and to advise governments on palliative care policy (World Health Assembly 2014).

### Augmenting the Essential Package

After the EP of palliative care and pain control is universally accessible, additional palliative medicines, equipment, and services should be made accessible by all countries to further prevent and relieve health-related suffering as soon as resources permit (Lutz, Jones, and Chow 2014; Miner 2005; Shulman and others 2015). This augmentation would consist of the following:

- Generic slow-release oral morphine or generic transdermal fentanyl patches
- Palliative surgery
- Palliative radiotherapy
- Palliative cancer chemotherapy
- Canes and wheelchairs.

In many LMICs, rehabilitation and long-term care services are either inadequate or inaccessible by the poor. As a result, community-based palliative care teams often assume responsibility for these tasks (Ratcliff and others 2017). However, all countries should develop policies and allocate funding specifically for the implementation of these much-needed services (World Health Assembly 2016).

## COSTS OF THE ESSENTIAL PACKAGE OF PALLIATIVE CARE AND PAIN CONTROL

In most LMICs, the cost of caring for patients with serious, complex, or life-limiting health problems is borne primarily not by governments but out-of-pocket by patients and their families. Serious, complex, or life-limiting health problems put patients' families at risk of financial ruin and caregivers at risk of exhaustion and health problems of their own (Emanuel and others 2008; Emanuel and others 2010). Data on the obvious and hidden costs of palliative care and any cost savings are important to inform governmental decisions about including palliative care among public health care services and about covering palliative care with government health insurance.

### Data on Costs and Cost Savings

Multiple studies from HICs indicate that palliative care can reduce costs for patients and families, as well as for health systems (Chalkidou and others 2014; DesRosiers and others 2014; Gomez-Batiste and others 2012; Jamison and others 2013; Summers 2016). Not only can palliative care improve patient outcomes, it also can reduce health care costs by reducing length of stay in the hospital, hospital admissions, and demand for expensive disease-modifying treatments of dubious benefit near the end of life. Patients who receive palliative care, especially early in their disease course, incur lower health care costs (Albanese and others 2013; May 2016; Morrison and others 2008), have shorter hospitalization (Morrison and others 2008; Postier and others 2014), enjoy equal or higher quality of life (Zimmerman and others 2008), and live equally long or longer (Elsayem and others 2004) than patients who do not receive palliative care. Palliative care also has been shown to increase satisfaction of family caregivers (Zimmerman and others 2008). Thus, evidence indicates that palliative care can generate positive externalities and can lower indirect costs to society, but data on costs and cost savings of palliative care in LMICs are limited (Emanuel and others 2010; Hongoro and Dinat 2011; Mosoiu, Dumitrescu, and Connor 2014).

### Method for Costing an Essential Package of Palliative Care and Pain Control in LMICs

To estimate the cost of delivering high-quality palliative care and pain control in LMICs, we used a method developed by the *Lancet* Commission (Knaul and others 2017). We obtained input from palliative care clinicians and global health experts with extensive experience in LMICs to devise a method of costing the EP of palliative care and pain control described in this chapter.

After creating the package of interventions, inexpensive essential medicines, simple equipment, human resources, and intersectoral social supports, as well as the sites or platforms where each part of the package should be accessible (table 12.2 and annex table 12A.1), we then estimated amounts of each item that would be required by patients with each ICD-10 health condition that generates a need for palliative care or pain control. We also estimated the staffing needs in full-time equivalents (FTEs) to apply the package at each site. Using WHO GHE mortality data (WHO 2016), we were able to estimate the total amount of medicines, equipment, and personnel FTEs, as well as the intersectoral social supports needed to provide palliative care and pain control to all patients in need in any country.

To determine the cost of delivering the EP in a specific country, we then identified the reported unit price of all medicines, equipment, social supports, and monthly FTE salaries of the palliative care providers in that country (De Lima and others 2014; McCoy and others 2008). The total cost of the EP was the total cost of all components. To cost human resources, we used monthly total pretax (including mandatory benefits), public sector, FTE-reported salaries. We also considered the most basic operational inputs required to support the provision of the EP at every level of care and added, on average, 8 percent to our overall figures.

### Application of the Method in Specific Countries

To provide examples for policy makers of the expected cost of the health care components of the EP per patient

in need of palliative care in one low-income country, one lower-middle-income country, and one upper-middle-income country, we applied our method in Rwanda, Vietnam, and Mexico (table 12.3) using the prices reported in each.

Not surprisingly, the cost of achieving universal access to the EP would require a much higher share of total government expenditure on health in Rwanda (between 7.0 and 10.0 percent) than in Mexico (less than 1.0 percent) or Vietnam (between 1.0 and 1.7 percent). As a proportion of gross domestic product, there would be an almost tenfold difference in cost of the EP between Rwanda (0.25 percent) and Mexico (0.03 percent) or Vietnam (0.04 percent).

We also produced preliminary estimates of the costs of the intersectoral social supports previously mentioned, considering only patients living in extreme poverty (daily income below US\$1.9) and a patient's one main caregiver living in extreme poverty (World Bank 2017). (These illustrative estimates assume that a stringent means test (screening process) can be implemented to identify those living in extreme poverty. However, experience with means tests in many places suggests that they may be costly to administer and subject to abuse.) Our assumption is that intersectoral social supports are both financed and provided by sectors of government working on poverty alleviation, and not by ministries of health. On the basis of data on subsidies provided to families by existing anti-poverty programs in Mexico, and given the small proportion of families below the poverty line (3 percent), the social supports would represent a very

**Table 12.3** Per Patient Cost of the Health Care Components of the Essential Package of Palliative Care and Pain Control in Mexico, Rwanda, and Vietnam, US\$, 2015 Current Value

	Rwanda <sup>d</sup>	Vietnam <sup>e</sup>	Mexico
<b>Medicines</b>	52	27	122
Morphine (oral or injectable)	20	14	90
<b>Equipment</b>	31	5	31
<b>Palliative care team (HR)</b>	121	78	584
<b>Operational Costs (8% of total)</b>	16	9	59
<b>Total</b>	<b>219</b>	<b>119</b>	<b>796</b>
% GDP <sup>a</sup>	0.25	0.04	0.03
% health expenditure <sup>b</sup>	3.35	0.56	0.50
% public health expenditure <sup>c</sup>	8.79	1.04	0.97

Note: GDP = gross domestic product; HR = human resources.

a. GDP, World Development Indicators, World Bank, <http://data.worldbank.org/indicator/NY.GDP.MKTP.CD>.

b. Health expenditure, total (% of GDP), World Development Indicators, World Bank, <http://data.worldbank.org/indicator/SH.XPD.TOTL.ZS>.

c. Health expenditure, public (% of total health expenditure), World Development Indicators, World Bank, <http://data.worldbank.org/indicator/SH.XPD.PUBL>.

d. For costing in Rwanda, the following substitutions were made: Fluoxetine was substituted with SSRI and reusable cloth diapers instead of disposable.

e. Costing in Vietnam does not include *Parenteral Fluconazole* as pricing for this medicine was unavailable in the country.

small additional cost, about 1 percent, compared to the health components of the EP. For Rwanda, as would be the case for other low-income countries, the total cost would be quite high, largely because more than 60 percent of families live in extreme poverty. Thus, the EP would have an anti-poverty function for the most financially vulnerable patients with palliative care needs and caregivers.

### Limitations of the Method

This costing method has several limitations. First, it does not include the costs of initial palliative care capacity building, including secure supply-chain building for controlled substances, human resource training and policy changes to officially integrate palliative care into the health care system and to ensure essential medicine accessibility. Second, our calculations are based on a particular model of palliative care delivery. For example, our model assumes that inpatient care is available at health centers for one patient at a time whose family is unable to provide adequate care in the home but who does not require higher-level care. Where inpatient care at health centers is not available, costs may differ. Our model includes estimated FTEs of all palliative care team members. Where larger or smaller FTEs are devoted to palliative care, costs will differ.

### CONCLUSIONS

A universally accessible EP of palliative care and pain control can prevent and relieve suffering for chronically or terminally ill patients. It is indispensable for achieving universal health coverage and for realizing Sustainable Development Goal 3: “ensure healthy lives and promote well-being for all at all ages” (United Nations General Assembly 2015, 16). It therefore is a medical and moral imperative to include such a package in publicly financed universal health coverage. In addition, the EP of palliative care and pain control that we propose may reduce costs for health care systems and national economies and provide financial risk protection for patients and their families.

To ensure that the EP of palliative care and pain control is universally accessible, governments should enact appropriate policies and ensure that health care providers have the necessary competencies by including training in palliative care and pain control in standard undergraduate and postgraduate curricula in medicine, nursing, and other clinical fields (Stjernswärd, Foley, and Ferris 2007; World Health Assembly 2014).

### ANNEX

The annex to this chapter is available at <http://www.dcp-3.org/DCP>.

- Annex 12A. The Essential Package of Palliative Care: Interventions, Medicines, Equipment, Human Resources, and Intersectoral Supports

### NOTES

This chapter was adapted from Knaul, F. M., P. E. Farmer, E. L. Krakauer, L. de Lima, A. Bhadelia, and others. 2017. “Alleviating the Access Abyss in Palliative Care and Pain Relief: An Imperative of Universal Health Coverage. Report of the *Lancet* Commission on Global Access to Palliative Care and Pain Control.” *The Lancet*. doi:10.1016/S0140-6736(17)32513-8.

World Bank Income Classifications as of July 2015 are as follows, based on estimates of gross national income (GNI) per capita for 2014:

- Low-income countries (LICs) = US\$1,045 or less
- Middle-income countries (MICs) are subdivided:
  - (a) lower-middle-income = US\$1,046 to US\$4,125
  - (b) upper-middle-income (UMICs) = US\$4,126 to US\$12,735
- High-income countries (HICs) = US\$12,736 or more.

### REFERENCES

- Abernethy, A. P., D. C. Currow, P. Frith, B. S. Fazekas, A. McHugh, and others. 2003. “Randomised, Double Blind, Placebo Controlled Crossover Trial of Sustained Release Morphine for the Management of Refractory Dyspnea.” *BMJ* 327: 523–29.
- Albanese, T. H., S. M. Radwany, H. Mason, C. Gayomali, and K. Dieter. 2013. “Assessing the Financial Impact of an Inpatient Acute Palliative Care Unit in a Tertiary Care Teaching Hospital.” *Journal of Palliative Medicine* 16 (3): 289–94.
- Bamberger, J. 2016. “Reducing Homelessness by Embracing Housing as a Medicaid Benefit.” *JAMA Internal Medicine* 176 (8): 1051–52.
- Belkin, G. S., J. Unutzer, R. C. Kessler, H. Verdell, G. J. Raviola, and others. 2011. “Scaling Up for the ‘Bottom Billion’; ‘5×5’ Implementation of Community Mental Health Care in Low-Income Regions.” *Psychiatric Services* 62 (12): 1494–1502.
- Carrillo, J. E., V. A. Carrillo, H. R. Perez, D. Salas-Lopez, A. Natale-Pereira, and others. 2011. “Defining and Targeting Health Care Access Barriers.” *Journal of Health Care for the Poor and Underserved* 22 (2): 562–75.
- Cassell, E. J. 1982. “The Nature of Suffering and the Goals of Medicine.” *New England Journal of Medicine* 306 (11): 639–45.
- Chalkidou, K., P. Marquez, P. K. Dhillon, Y. Teerawattananon, T. Anothaisintawee, and others. 2014. “Evidence-Informed

- Frameworks for Cost-Effective Cancer Care and Prevention in Low, Middle, and High-Income Countries.” *The Lancet Oncology* 15 (3): e119–31. [http://dx.doi.org/10.1016/S1470-2045\(13\)70547-3](http://dx.doi.org/10.1016/S1470-2045(13)70547-3).
- Connor, S., B. Pyenson, K. Fitch, C. Spence, and K. Iwasaki. 2007. “Comparing Hospice and Non-Hospice Patient Survival among Patients Who Die within a Three-Year Window.” *Journal of Pain and Symptom Management* 33 (3): 238–46.
- Connor, S., and M. C. Sepulveda Bermedo, eds. 2014. *Global Atlas of Palliative Care at the End of Life*. London: Worldwide Palliative Care Alliance. [http://www.who.int/nmh/Global\\_Atlas\\_of\\_Palliative\\_Care.pdf](http://www.who.int/nmh/Global_Atlas_of_Palliative_Care.pdf).
- De Lima, L., T. Pastrana, L. Radbruch, and R. Wenk. 2014. “Cross-Sectional Pilot Study to Monitor the Availability, Dispensed Prices, and Affordability of Opioids around the Globe.” *Journal of Pain and Symptom Management* 48 (4): 649–59.
- DesRosiers, T., C. Cupido, E. Pitout, L. van Niekerk, M. Badri, and others. 2014. “A Hospital-Based Palliative Care Service for Patients with Advanced Organ Failure in Sub-Saharan Africa Reduces Admissions and Increases Home Death Rates.” *Journal of Pain and Symptom Management* 47 (4): 786–92.
- Dowell, D., T. M. Haegerich, and R. Chou. 2016. “CDC Guideline for Prescribing Opioids for Chronic Pain—United States.” *MMWR* 65 (1): 1–48.
- Doyle, K. E., S. K. El Nakib, M. R. Rajagopal, S. Babu, G. Joshi, and others. 2017. “Predictors and Prevalence of Pain and Its Management in Four Regional Cancer Hospitals in India.” *Journal of Global Oncology*. <http://ascopubs.org/doi/pdf/10.1200/JGO.2016.006783>.
- Elsayem, A., K. Swint, M. J. Fisch, J. L. Palmer, S. Reddy, and others. 2004. “Palliative Care Inpatient Service in a Comprehensive Cancer Center: Clinical and Financial Outcomes.” *Journal of Clinical Oncology* 22 (10): 2008–14.
- Emanuel, N., M. A. Simon, M. Burt, A. Joseph, N. Sreekumar, and others. 2010. “Economic Impact of Terminal Illness and the Willingness to Change It.” *Journal of Palliative Medicine* 13 (8): 941–44.
- Emanuel, R. H., G. A. Emanuel, E. B. Reitschuler, A. J. Lee, E. Kikule, and others. 2008. “Challenges Faced by Informal Caregivers of Hospice Patients in Uganda.” *Journal of Palliative Medicine* 11 (5): 746–53.
- Farmer, P. E., B. Nizeye, S. Stulac, and S. Keshavjee. 2006. “Structural Violence and Clinical Medicine.” *PLoS* 3 (10): e449. <http://journals.plos.org/plosmedicine/article?id=10.1371/journal.pmed.0030449>.
- Foley, K. M., J. L. Wagner, D. E. Joranson, and H. Gelband. 2006. “Pain Control for People with Cancer and AIDS.” In *Disease Control Priorities in Developing Countries* (second edition), edited by D. T. Jamison, J. G. Breman, A. R. Measham, G. Alleyne, M. Claeson, D. B. Evans, P. Jha, A. Mills, and P. Musgrove. Washington, DC: World Bank.
- Gaskin, D. J., and P. Richard. 2011. “Appendix C: The Economic Costs of Pain in the United States.” In *Institute of Medicine. Relieving Pain in America: A Blueprint for Transforming Prevention, Care, Education, and Research*, 301–37. Washington DC: National Academies Press. <https://www.ncbi.nlm.nih.gov/books/NBK92521/>.
- Gomez-Batiste, X., C. Caja, J. Espinosa, I. Bullich, M. Martinez-Muñoz, and others. 2012. “The Catalonia World Health Organization Demonstration Project for Palliative Care Implementation: Quantitative and Qualitative Results at 20 Years.” *Journal of Pain Symptom Management* 43 (4): 783–94.
- Gwyther, L., and E. L. Krakauer. 2011. “WPCA Policy Statement on Defining Palliative Care.” Worldwide Palliative Care Alliance, London. <http://www.thewhpc.org/resources/item/defining-palliative-care>.
- Herce, M. E., S. N. Elmore, N. Kalanga, J. W. Keck, E. B. Wroe, and others. 2014. “Assessing and Responding to Palliative Care Needs in Rural Sub-Saharan Africa: Results from a Model Intervention and Situation Analysis in Malawi.” *PLoS One* 9 (10): e110457. <http://www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.01110457>.
- Higginson, J., C. Bausewein, C. C. Reilly, W. Gao, M. Gysels, and others. 2014. “An Integrated Palliative and Respiratory Care Service for Patients with Advanced Disease and Refractory Breathlessness: A Randomised Controlled Trial.” *The Lancet Respiratory Medicine* 2 (12): 979–87.
- Hongoro, C., and N. Dinat. 2011. “A Cost Analysis of a Hospital-Based Palliative Care Outreach Program: Implications for Expanding Public Sector Palliative Care in South Africa.” *Journal of Pain and Symptom Management* 41 (6): 1015–24.
- Jamison, D. T., L. H. Summers, G. Alleyne, K. J. Arrow, S. Berkley, and others. 2013. “Global Health 2035: A World Converging within a Generation.” *The Lancet* 382 (9908): 1898–955.
- Joranson, D., M. Maurer, and F. Mwangi-Powell, eds. 2010. “Guidelines for Ensuring Patient Access to, and Safe Management of, Controlled Medicines.” Kampala: African Palliative Care Association. [http://integratepc.org/wp-content/uploads/2013/05/patient\\_access1.pdf](http://integratepc.org/wp-content/uploads/2013/05/patient_access1.pdf).
- Knaul, F. M., P. E. Farmer, E. L. Krakauer, L. de Lima, A. Bhadelia, and others. 2017. “Alleviating the Access Abyss in Palliative Care and Pain Relief: An Imperative of Universal Health Coverage. Report of the Lancet Commission on Global Access to Palliative Care and Pain Control.” *The Lancet*. doi:10.1016/S0140-6736(17)32513-8.
- Krakauer, E. L. 2008. “Just Palliative Care: Responding Responsibly to the Suffering of the Poor.” *Journal of Pain and Symptom Management* 36 (5): 505–12.
- Lutz, S. T., J. Jones, and E. Chow. 2014. “Role of Radiation Therapy in Palliative Care of the Patient with Cancer.” *Journal of Clinical Oncology* 32 (26): 2913–19.
- Mathers, C., G. Stevens, D. Hogan, A. Mahanani, and J. Ho. 2018. “Global and Regional Causes of Death: Patterns and Trends, 2000–15.” In *Disease Control Priorities* (third edition): Volume 9, *Improving Health and Reducing Poverty*, edited by D. T. Jamison, H. Gelband, S. Horton, P. Jha, R. Laxminarayan, C. N. Mock, and R. Nugent. Washington, DC: World Bank.
- May, P., M. M. Garrido, J. B. Cassel, A. S. Kelley, D. E. Meier, and others. 2016. “Palliative Care Teams’ Cost-Saving Effect Is Larger for Cancer Patients with Higher Numbers of Comorbidities.” *Health Affairs* 35 (1): 44–53.
- McCoy, D., S. Bennett, S. Witter, B. Pond, B. Baker, and others. 2008. “Salaries and Incomes of Health Workers in Sub-Saharan Africa.” *The Lancet* 371 (9613): 675–81.

- Miner, T. J. 2005. "Palliative Surgery for Advanced Cancer: Lessons Learned in Patient Selection and Outcome Assessment." *American Journal of Clinical Oncology* 28 (4): 411–14.
- Moens, K., I. J. Higginson, and R. Harding. 2014. "Are There Differences in the Prevalence of Palliative Care-Related Problems in People Living with Advanced Cancer and Eight Non-Cancer Conditions? A Systematic Review." *Journal of Pain and Symptom Management* 48 (4): 660–77.
- Morrison, R. S., J. D. Penrod, J. B. Cassel, M. Caust-Ellenbogen, A. Litke, and others. 2008. "Cost Savings Associated with U.S. Hospital Palliative Care Consultation Programs." *Archives of Internal Medicine* 168 (16): 1783–90.
- Mosoiu, D., M. Dumitrescu, and S. R. Connor. 2014. "Developing a Costing Framework for Palliative Care Services." *Journal of Pain and Symptom Management* 48 (4): 719–29.
- Ostgathe, C., B. Alt-Epping, H. Golla, J. Gaertner, G. Lindena, and others. 2011. "Non-Cancer Patients in Specialized Palliative Care in Germany: What Are the Problems?" *Palliative Medicine* 25 (2): 148–52.
- Pain and Policy Studies Group. 2017. Opioid Consumption Data. Madison, University of Wisconsin. <http://www.painpolicy.wisc.edu/opioid-consumption-data>.
- Patel, V. 2014. *Where There Is No Psychiatrist*. London: Gaskell.
- Postier, A., J. Chrastek, S. Nugent, K. Osenga, and S. J. Friedrichsdorf. 2014. "Exposure to Home-Based Pediatric Palliative and Hospice Care and Its Impact on Hospital and Emergency Care Charges at a Single Institution." *Journal of Palliative Medicine* 17 (2): 183–88.
- Rahman, A., S. U. Hamdani, N. R. Awan, R. A. Bryant, K. S. Dawson, and others. 2016. "Effect of a Multicomponent Behavioral Intervention in Adults Impaired by Psychological Distress in a Conflict-Affected Area of Pakistan: A Randomized Clinical Trial." *Journal of the American Medical Association* 316 (24): 2609–17.
- Ratcliff, C., A. Thyle, S. Duomai, and M. Manak. 2017. "Poverty Reduction in India through Palliative Care: A Pilot Project." *Indian Journal of Palliative Care* 23 (1): 41–45.
- Shulman, L. N., T. Mpunga, N. Tapela, C. M. Wagner, T. Fadelu, and others. 2014. "Bringing Cancer Care to the Poor: Experiences from Rwanda." *Nature Reviews Cancer* 14 (12): 815–21.
- Shulman, L. N., C. M. Wagner, R. Barr, G. Lopes, G. Longo, and others. 2015. "Proposing Essential Medicines to Treat Cancer: Methodologies, Processes, and Outcomes." *Journal of Clinical Oncology* 34 (1): 69–75.
- Singer, A. E., J. R. Goebel, Y. S. Kim, S. M. Dy, S. C. Ahluwalia, and others. 2016. "Populations and Interventions for Palliative and End-of-Life Care: A Systematic Review." *Journal of Palliative Medicine* 19 (9): 995–1008. doi:10.1089/jpm.2015.0367.
- Solano, J. P., B. Gomes, and I. J. Higginson. 2006. "A Comparison of Symptom Prevalence in Far Advanced Cancer, AIDS, Heart Disease, Chronic Obstructive Pulmonary Disease and Renal Disease." *Journal of Pain and Symptom Management* 31 (1): 58–69.
- Stjernsward, J., K. M. Foley, and F. D. Ferris. 2007. "The Public Health Strategy for Palliative Care." *Journal of Pain and Symptom Management* 33 (5): 486–93.
- Summers, L. H. 2016. "No Free Lunches but Plenty of Cheap Ones." *Larry Summers's Blog*, February 7. <http://larrysummers.com/2016/02/08/no-free-lunches-but-plenty-of-cheap-ones/>.
- Syed, S. T., B. S. Gerber, and L. K. Sharp. 2013. "Traveling towards Disease: Transportation Barriers to Health Care Access." *Journal of Community Health* 38 (5): 976–93.
- Temel, J. S., J. A. Greer, A. Muzikansky, E. R. Gallagher, S. Admane, and others. 2010. "Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer." *New England Journal of Medicine* 363 (8): 733–742.
- United Nations General Assembly. 2015. "Transforming Our World: The 2030 Agenda for Sustainable Development." UNGA A/RES/70/1. [http://www.un.org/ga/search/view\\_doc.asp?symbol=A/RES/70/1&Lang=E](http://www.un.org/ga/search/view_doc.asp?symbol=A/RES/70/1&Lang=E).
- Van den Beuken-van Everdingen, M. H. J., L. J. Hochstenbach, and E. A. J. Joosten. 2016. "Update on Prevalence of Pain in Patients with Cancer: Systematic Review and Meta-Analysis." *Journal of Pain and Symptom Management* 51 (6): 1070–90.
- WHO (World Health Organization). 1996. *Cancer Pain Relief, with a Guide to Opioid Availability* (second edition). Geneva: WHO. <http://apps.who.int/iris/bitstream/10665/37896/1/9241544821.pdf>.
- . 2002. "Definition of Palliative Care." WHO, Geneva. <http://www.who.int/cancer/palliative/definition/en/>.
- . 2006. "Amended Constitution of the World Health Organization." [http://www.who.int/governance/eb/who\\_constitution\\_en.pdf](http://www.who.int/governance/eb/who_constitution_en.pdf).
- . 2011. *Ensuring Balance in National Policies on Controlled Substances: Guidance for Availability and Accessibility of Controlled Medicines*. Geneva: WHO. [http://www.who.int/medicines/areas/quality\\_safety/GLs\\_Ens\\_Balance\\_NOCP\\_Col\\_EN\\_sanend.pdf](http://www.who.int/medicines/areas/quality_safety/GLs_Ens_Balance_NOCP_Col_EN_sanend.pdf).
- . 2012. *WHO Guidelines on the Pharmacological Treatment of Persisting Pain in Children with Medical Illnesses*. Geneva: WHO. [http://apps.who.int/iris/bitstream/10665/44540/1/9789241548120\\_Guidelines.pdf](http://apps.who.int/iris/bitstream/10665/44540/1/9789241548120_Guidelines.pdf).
- . 2015a. WHO International Classification of Diseases (ICD)-10. Geneva: WHO. <http://apps.who.int/classifications/icd10/browse/2015/en>.
- . 2015b. "WHO Model List of Essential Medicines, 19th list." Geneva, WHO. <http://www.who.int/medicines/publications/essentialmedicines/en/index.html>.
- . 2015c. "WHO Model List of Essential Medicines for Children, 5th list." WHO, Geneva. <http://www.who.int/medicines/publications/essentialmedicines/en/index.html>.
- . 2016. "Cause-Specific Mortality." WHO, Geneva. [http://www.who.int/healthinfo/global\\_burden\\_disease/estimates/en/index1.html](http://www.who.int/healthinfo/global_burden_disease/estimates/en/index1.html).
- . 2017. "WHO Methods and Data Sources for Country-Level Causes of Death 2000–2015." Geneva: WHO. [http://www.who.int/healthinfo/global\\_burden\\_disease/GlobalCOD\\_method\\_2000\\_2015.pdf](http://www.who.int/healthinfo/global_burden_disease/GlobalCOD_method_2000_2015.pdf).

- World Bank. 2017. "Poverty Headcount Ratio at \$1.90 a Day (2011 PPP) (% of Population)." World Bank, Washington, DC. <http://data.worldbank.org/indicator/SI.POV.DDAY>.
- World Health Assembly. 2014. "Strengthening of Palliative Care as a Component of Comprehensive Care throughout the Life Course." WHA 67.19. [http://apps.who.int/gb/ebwha/pdf\\_files/WHA67/A67\\_R19-en.pdf](http://apps.who.int/gb/ebwha/pdf_files/WHA67/A67_R19-en.pdf).
- . 2016. "Multisectoral Action for a Life Course Approach to Healthy Ageing: Draft Global Strategy and Plan of Action on Ageing and Health." WHA A69/17. [http://apps.who.int/gb/ebwha/pdf\\_files/WHA69/A69\\_17-en.pdf](http://apps.who.int/gb/ebwha/pdf_files/WHA69/A69_17-en.pdf).
- Zimmerman, C., R. Riechelmann, M. Krzyzanowska, G. Rodin, and I. Tannock. 2008. "Effectiveness of Specialized Palliative Care: A Systematic Review." *Journal of the American Medical Association* 299 (14): 1698–709.
- Zimmerman, C., N. Swami, M. Krzyzanowska, B. Hannon, N. Leighl, and others. 2014. "Early Palliative Care for Patients with Advanced Cancer: A Cluster-Randomised Controlled Trial." *The Lancet* 383 (9930): 1721–30. [http://dx.doi.org/10.1016/S0140-6736\(13\)62416-2](http://dx.doi.org/10.1016/S0140-6736(13)62416-2).