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Opportunities for Palliative Care in Public Health

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Abstract

In May 2014, the World Health Assembly, of the World Health Organization (WHO), unanimously adopted a palliative care (PC) resolution, which outlines clear recommendations to the United Nations member states, such as including PC in national health policies and in the undergraduate curricula for health care professionals, and highlights the critical need for countries to ensure that there is an adequate supply of essential PC medicines, especially those needed to alleviate pain. This resolution also carries great challenges: Every year over 20 million patients (of which 6% are children) need PC at the end of life (EOL). However, in 2011, approximately three million patients received PC, and only one in ten people in need is currently receiving it. We describe this public health situation and systems failure, the history and evolution of PC, and the components of the WHO public health model. We propose a role for public health for PC integration in community settings to advance PC and relieve suffering in the world.

Noncommunicable disease: a medical condition or chronic disease that is noninfectious or nontransmissible

Palliative care (PC): the holistic care of patients with a life-threatening diagnosis and of their families

End of life (EOL): the last few weeks or days of life when a person is irreversibly dying (terminal phase)

World Health Organization (WHO): a specialized agency of the United Nations that is concerned with international public health

Public health: all organized measures (whether public or private) to prevent disease, promote health, and prolong life among the population as a whole

INTRODUCTION

Care for people with chronic, incurable, and debilitating illnesses is a major global challenge. Approximately 55 million people died in 2011; two-thirds of these deaths were caused by noncommunicable diseases, such as cardiovascular conditions, cancer, diabetes, and chronic obstructive pulmonary disease (76). In addition, the population is also aging faster, and people are living longer and suffering from multiple chronic conditions with palliative care (PC) needs in early stages of the disease as well as during end of life (EOL) (1).

The *Global Atlas of Palliative Care at the End of Life*, published by the Worldwide Palliative Care Alliance jointly with the World Health Organization (WHO), estimated that every year more than 20 million patients need PC—6% of these are children (19).

Most of the progress in the PC field has been on the quality of service provision at the bedside, which is focused on the relief of physical symptoms, and on services addressing the emotional, social, and spiritual distress of patients and their families. This patient- and family-centered approach has been useful in generating awareness about patients' needs and relief of suffering, but the approach has had limited applicability at the public health level. For example, the recommendations and outcomes of patient care have limited applicability when governments desire to develop and implement policies and allocate resources to address the needs of the population.

In the majority of cases, the development of PC has been scaled up from initiatives that eventually were included in hospitals and clinics as PC units and PC programs. These programs and services usually lack recognition from the government programs, and therefore reimbursement, budget, and resource allocation are mostly unavailable, making these very fragile programs with limited viability. In order for PC strategies to be effective, they must become part of the health care services covered by government programs and be implemented at all levels of health care systems.

In this review, we first present PC issues as a public health priority. Then, we describe this public health crisis, the history and evolution of PC, and the components of WHO's public health model. WHO as well as several nongovernmental organizations and public health experts advocate better integration of palliative care in community settings to improve accessibility to patients in need. For the purpose of this review, we used the following definition of community (46, p. 1936): "a group of people with diverse characteristics who are linked by social ties, share common perspectives, and engage in joint action in geographical locations or settings."

WHAT IS PALLIATIVE CARE?

WHO has defined PC as an approach that improves the quality of life of patients, and their families, facing the problems associated with life-threatening illness through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, including physical, psychosocial, and spiritual. The WHO definition further states that PC (75, p. 84):

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient's illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness; and

- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

PC relieves suffering and improves quality of life for both patients and families throughout an illness, not just at the EOL (66). During the past decade, studies have demonstrated the benefit of providing PC earlier in the course of illness in conjunction with disease modifying treatment (68). However, for this review, we focus on PC in advanced illness and in EOL care. Most of the recommendations and comments included in this article are applicable to patients with PC needs regardless of the stage of their disease.

BRIEF HISTORY OF PALLIATIVE CARE

The palliation of pain and other symptoms has always been a part of medical care. However, it has received very limited attention in modern medicine, and until recently, physicians and nurses had very little or no training in the subject. During the nineteenth century, the most important breakthroughs in pain treatment included general and local anesthesia as well as analgesic drugs from morphine to anti-inflammatory nonsteroidal agents. Modern analgesics were synthesized, and new invasive procedures were approved, which had a major impact on pain management strategies.

PC developed in the second half of the twentieth century when different efforts converged into the complex field it is today. Physicians (mostly anesthesiologists) working in the alleviation of severe, chronic, and malignant pain were confronted with patients who were in incurable and progressive stages of a disease. This resulted in many of them focusing on treatment of pain for patients in terminal stages, who had, in addition to pain, a myriad of other symptoms.

Cicely Saunders, an English social worker, nurse, and physician, in 1967 founded Saint Christopher's Hospice in South London, considered the first modern hospice. St. Christopher's included teaching for physicians and implemented research protocols to evaluate the impact of the provision of therapeutic strategies on the quality of patients' life. Dr. Saunders, coined the term total pain to describe the physical, psychological, social, and spiritual suffering of patients. In 1974, the Royal Victoria Hospital in Montreal, Canada, started a new unit following St. Christopher's example, but the term hospice did not have a good translation to French. Balfour Mount, one of the founders of the program in Royal Victoria, coined the term palliative care, and this term has since been used to name the field (44).

In 1986, WHO and its Expert Committee on Cancer Pain Relief and Active Supportive Care developed WHO's Cancer Pain Relief Program (73, p. 19), calling cancer pain "a ubiquitous but neglected public health problem," raising awareness that every day more than three and a half million people suffered from cancer pain but that only a fraction received treatment. The core of the WHO Cancer Pain Relief Program was the WHO analgesic ladder, a method for the relief of cancer pain, which, although not based on evidence, proved to be very effective in achieving pain relief using inexpensive medications. This analgesic ladder was widely disseminated in a campaign called Why not freedom from cancer pain? The ladder is still implemented with some modifications and relies on the availability of oral opioid analgesics, including morphine, codeine, and other adjuvant medications.

According to Clark & Graham (16, p. 636), four key health care developments were identified by the middle years of the twentieth century:

- The professional literature about the care of the dying started to shift from anecdote to systematic observation.

- A new view of dying began to emerge which sought to foster concepts of personal dignity, autonomy and meaning at the EOL.
- An active rather than a passive approach to the care of the dying was promoted with increasing interest.
- A growing understanding developed about the interdependency of mental and physical distress at the end of life.

WHY IS PALLIATIVE CARE A PUBLIC HEALTH ISSUE?

Death has a universal incidence: Regardless of all the advances in prevention and curative treatment, all of us will eventually die. In spite of this, PC has received very little attention in the field of public health. The probable reasons are that public health's primary focuses are to prevent illness and premature deaths, and public health professionals may also believe that end-of-life issues are a health system problem rather than a priority to be addressed through population health efforts. In this section, we present the following data to demonstrate that PC is a public health issue.

1. The causes of death have changed, altering the provision of care and impacting health care systems. More people are dying from chronic diseases rather than from acute illnesses. For example, in 1900 in many countries, the leading causes of death were communicable diseases, including tuberculosis and diarrheal diseases in children (37). Nowadays, the top five predicted causes of death are heart disease, cerebrovascular disease/stroke, chronic respiratory disease, respiratory infections, and lung cancer. With chronic diseases, millions experience slow and, in many cases, painful deaths.
2. The population is living longer and aging. In the European Union, the proportion of people aged 65 years or over in the total population is projected to increase from 17.1% in 2008 to 30.0% in 2060, with the number rising from 84.6 million to 151.5 million (17). According to projections by the United Nations, the number of people aged 80 years and over worldwide will rise from 102 million in 2009 to 395 million in 2050. The United Nations predicts that by 2050, nearly 25% of the world's population will be over 60 years old, and nearly 80% of the world's older population will live in the less-developed regions (69). By the year 2030, according to the Administration on Aging, there will be more than 72.1 million Americans over age 65 in the United States (20% of the total U.S. population), which is more than twice the number in 2000 (49).
3. Health care systems cannot afford to not have PC. The provision of care for patients with life-limiting illnesses who do not have access to PC is quite expensive for health systems. In the past decades, the costs of care in the United States associated with the last year of life for Medicare beneficiaries have been consistently about one-third of the overall Medicare expenditures, with one-third of that occurring in the last month of life (8). In the United Kingdom, 22% of bed days are occupied by people in their last year of life (12). In the United States in 2010, the average amount spent per chronically ill Medicare patient in the last two years of life was US\$69,947 (22). End-of-life costs are only slightly higher for persons who died than for survivors with similar characteristics, due to the excessive use of costly diagnostic exams and therapeutic approaches in patients facing EOL (38).

A systematic review suggests that PC services can transfer costs from hospitals to home care (36). Studies in the United States show that PC services reduced hospital admissions (3, 20), reduced costs to 45%, and increased patient satisfaction (9, 10). Despite the high costs, there is a scarcity of research into effective and cost-effective solutions. In 2010, US federal agencies spent US\$61.55 million for EOL PC research, a large increase from the US\$4.23 million spent in 1997. During that period, 37 federal organizations supported

new EOL PC research grants, including the National Institutes of Health (NIH), the US Department of Veterans Affairs, the Agency for Healthcare Research and Quality, the US Public Health Service, the Health Resources and Services Administration, and the Centers for Disease Control and Prevention, among others (50). Despite these gains, US EOL PC research funding represents only a fraction of the total mandated funds in biomedical science research. In the United Kingdom, in 2010, only 0.24% of research funding was devoted to palliative and end-of-life care (63).

On a microlevel, many families face financial devastation when a family member develops a chronic, progressive illness or suffers a crippling injury. This includes losing their primary source of income or loss of most or all of their savings (26, 27, 56). The annual monetary value of informal caregiving in the United States has been estimated at US\$350 billion (28).

4. End-of-life issues have a huge impact on the dying person's family (64, 70). It is estimated that each death potentially affects the life of on average five people in terms of caregiving and grieving. By 2030, there will be an estimated 74 million deaths per year, which will increase the number of people affected by death and dying per year to 370 million. For some families and caregivers, the illnesses of a loved one can produce major, often unexpected life changes as well as an increased likelihood of depressive symptoms and mortality among the caregivers of terminally ill patients (21, 25, 58, 61).

It is estimated that globally there are over 400,000 PC staff workers, over 1.2 million volunteers, and over 9 million people acting as palliative caregivers. This means that over 10.5 million people are involved with delivering hospice and PC every year. The vast majority of care for the chronically ill and frail elderly has traditionally been and continues to be provided by individual networks of relatives and close friends. Approximately 25.8 million individuals in the United States spend an average of 18 hours a week caring for frail relatives, and more than half of the population (54%) anticipate being responsible for the care of an elderly parent or relative within the next 10 years. Demographic and economic pressures, however, are making it harder for families to be available when needed. A diminished birthrate in many developed countries, an increased proportion of multiple-job couples, and heightened geographic mobility within families reduce the pool of caregivers (11). With the exception of Costa Rica where the government provides a subsidy and up to six months of paid leave from work to individuals who are caring for a patient with less than six months of life expectancy (5), family members in other countries are poorly rewarded for providing care for chronically ill loved ones (11). The burden of caregiving is associated with significant emotional and physical symptoms, increased use of health services, and a 63% higher mortality risk among caregivers compared with noncaregivers (61).

Evidence of Unmet Needs

Throughout the world, many patients with advanced diseases present late to their health care system, and therapies to control their diseases are frequently ineffective. For these patients, PC gives the greatest benefit for low cost during their limited life expectancy (67). Patients facing EOL have multiple symptoms and problems, which cause suffering, e.g., pain, dyspnea, nausea, fatigue, as well as psychosocial symptoms, such as depression and anxiety. Tragically, although the knowledge and experience to diminish these symptoms exist, most of the world's population has no access to PC. In fact, the greatest need is in developing countries, where 78% of adults in need of palliative care live and health care resources are the scarcest (19, 67). The situation is also tragic for children with palliative care needs (13). Despite the lack of attention and funding, there are reports in the literature indicating that positive developments have taken place throughout the

Public health strategy (PHS):

a strategy pioneered by WHO to integrate palliative care into existing health care systems and programs

world. In 2011, 136 (58%) of the world's 234 countries had at least one PC service—an increase of 21 (9%) from 2006, with the most substantial gains made in Africa (57).

In the United States, PC initial development and progress were largely due to projects such as Project Death in America, whose aim was to understand and transform the culture and experience of dying through initiatives in research and scholarship, the arts and humanities, innovations in the provision of care, public and professional education, and public policy (6). For over a decade, this project supported and provided funding for US organizations, universities, institutions, and individuals, which allowed them to become the field's US experts in this research and to be pivotal for the advancement of the field. However, in spite of the growth and utilization of palliative and hospice care services in the United States, a 2003 Hastings report indicated that over one million Americans died each year without accessing any hospice or PC services (40). For example, in 2010, the number of enrollees in Medicare hospice benefits increased to over one million from slightly half a million in 2000, but more than half of the enrollees (53.4%) used hospice for either a very short period of time (≤ 1 week, 32.4%) or very long (> 6 months, 13.9%), and over 10% were disenrolled from hospice before death. Patients with noncancer diagnoses, the fastest growing group of hospice users, were approximately twice as likely as those with cancer to have very short or long enrollment periods and to disenroll from hospice (2). Studies also show that even patients with advanced, incurable disease are not referred to hospice or palliative care programs (52).

Unfortunately, there are also large inequities in access to pain treatment: High-income countries account for more than 90% of the global consumption of medical opioids, and an estimated four billion people live in countries where there is limited access to opioids. Lack of access affects all controlled medicines on the WHO Model List of Essential Medicines (77) and the WHO Model List of Essential Medicines for Children (http://www.who.int/medicines/publications/essentialmedicines/EMLc2015_8-May-15.pdf). The challenges and obstacles to accessing palliative care and pain treatment include undue restrictions and constraints in national policies, deficiencies in medical and nursing education, limited resources, the high cost of medications, the abuse of prescription opioids in the United States and other high-income countries, and the attitudinal barriers of health providers and the public (11, 15, 24). The deficiencies of care include not only significant gaps in medical care for those with serious, chronic illnesses but also lack of support for their families.

THE WORLD HEALTH ORGANIZATION: RESOLUTION AND STRATEGY

In 1990, WHO pioneered a public health strategy (PHS) to integrate PC into existing health care systems. This included advice and guidelines to governments on priorities and how to implement national PC programs and national cancer control programs where PC should be one of the key components of comprehensive care. The WHO PHS initially included three components: (a) appropriate policies, (b) adequate availability of medications, and (c) education of health care workers and the public. On the basis of the experiences with this model and the implementation processes, an enhanced public health model later emerged in which a fourth component was added, implementation of PC services at all levels throughout society, and in which the policy component was elevated to cover all the rest (Figure 1).

To effectively integrate PC into a society and change the experience of patients and families, all four components of the WHO public health model must be addressed. This process is always meant to be implemented within the context of the culture, disease demographics, socioeconomics, and health care system of the country. For each component, there are short, intermediate, and long-term outcomes that must be measured (67). Even though this WHO PHS was initially

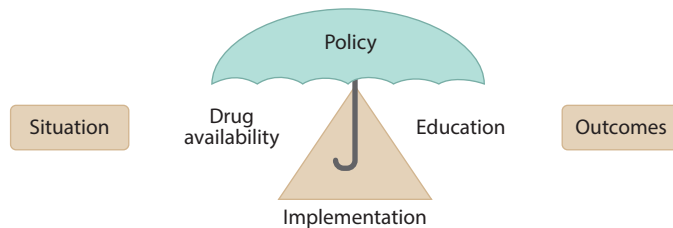


Figure 1

The World Health Organization's public health model. Reprinted with permission from Stjernsward et al. (67). 2007. The public health strategy for palliative care. *Journal of Pain and Symptom Management* 33(5):486–93.

developed for national cancer control programs, it is applicable to other conditions and national programs.

Public Health Approach

WHO has identified the formulation and implementation of the following policies as essential for expanding PC within a public health approach:

- Health system policies to ensure the integration of PC services into the structure and financing of national health care systems at all levels of care
- Policies for strengthening and expanding human resources, including education and training of health care professionals together with training of volunteers and education of the public, to ensure adequate responses to the PC needs
- A policy that ensures the availability of essential medicines for the management of symptoms, including pain and psychological distress, and, in particular, opioid analgesics for relief of pain and respiratory distress
- A policy of providing research into assessing the needs for PC and identifying standards and models of service that work, particularly in limited-resource settings

Many of the services and interventions for providing PC are already within the reach of most countries, including those in the low- and middle-income range. Actions that can support the extension and strengthening of services for PC at the country level include the following:

1. Formulating and implementing national policies that integrate evidence-based palliative services into the continuum of care at all levels of chronic life-threatening conditions with an emphasis on primary care and community- and home-based care
2. Advocating for PC in efforts to promote universal health coverage and essential medicine policies based on the results of assessment and improvement of the quality and safety of PC
3. Implementing and monitoring the recommendations in the global action plan for the prevention and control of noncommunicable diseases 2013–2020 and ensuring their integration into universal coverage and an essential medicine plan
4. Ensuring that education about PC (including ethical aspects) is offered to students in undergraduate medical and nursing schools and to health care providers at all levels in accordance with their roles and responsibilities and as part of human resource development
5. Ensuring adequate access to controlled medicines while minimizing opportunities for their diversion and abuse by aligning national and local regulations with WHO's guidance on national policies for controlled substances
6. Ensuring access to all aspects of PC (basic medical support and psychosocial and spiritual support to patients and families) under the supervision of trained health care professionals

World Health Assembly (WHA):

the decision-making and governing body of World Health Organization, attended by delegations from all WHO member states

7. Establishing ethical guidance related to the provision of PC, such as equitable access, respectful care, and community involvement in policies and programs
8. Working in partnership with different sectors to foster operational research in PC, including the development of cost-effective models of such care

In May 2014, the World Health Assembly (WHA)—the governing body of WHO—unanimously adopted a groundbreaking resolution urging countries to ensure access to PC for people with life-threatening illnesses (72). The resolution outlines clear recommendations, such as including PC in all national health policies and budgets and in the curricula for health professionals, and highlights the critical need for countries to ensure that there is an adequate supply of essential PC medicines, including those needed to alleviate pain and other symptoms. These issues are discussed in the following subsections.

Assessment and Monitoring

Public health has been very successful in developing surveillance systems and measures to assess the health of the entire population. Usually, public health tools are practical to administer, comprehensible to the public, and sensitive to population variability (34). In addition, these measures provide representative data of the health experiences of the whole population as well as of various subpopulations (34).

For many years, the PC community has advocated for systematic monitoring of PC at national and global levels. Global health has been marked by a lack of interest and investment to provide and monitor access to PC and measure the relief of suffering; none of the global funders include PC in their programs, and the single proposed PC indicator for WHO's noncommunicable diseases strategy was not included in the resulting plan (57). In the United States, Medicare funding, which supports most of the postmedical school residence training for physicians, does not support palliative medicine specialty training (49). Priority-setting methods and conventional guidelines are focused on strategies that value extending life and increasing economic productivity. In the United States, since 1971 when President Nixon declared the war on cancer, the word war has been the prevailing metaphor used to describe and combat cancer. The use of this metaphor identifies and defines the allies and enemies, winners and losers, victors and victims (32). This language may help those who are in curable stages or responding positively to curative approaches, but it is not helpful for patients with incurable conditions or for those who do not respond to curative treatments and are in advanced stages facing EOL (33).

Several PC organizations have published reports on the status of national, regional, and global PC development (14, 45, 53); however, these reports have had limited impact on the monitoring of PC by member states. A systematic review of PC indicators developed by several organizations and PC groups also demonstrated that the vast majority of indicators are focused on the quality of care provisions and patient outcomes (65). These indicators have proven to be useful at the patient and care provider levels, but they have limited applicability in population studies, and policy makers have limited information on which indicators can be used at the national level.

The WHA resolution discussed in the previous section requests member states to report back to the WHA on the progress they have achieved in implementing PC in their countries. However, in the recently published WHO Global Reference List of 100 Core Health Indicators (78), a standard set of indicators prioritized by the global community to provide concise information on the health situation and trends, a proposed PC indicator [access to PC assessed by morphine-equivalent consumption of strong opioid analgesics (excluding methadone) per death from cancer] was not included, making it hard for countries to fulfill their obligation to report on their progress.

Table 1 Latin American Association for Palliative Care's (ALCP's) palliative care indicators (53, 54)

Health care policy
PO1. Existence of a current national palliative care (PC) plan/program (yes/no)
Education
ED1. Proportion of medical schools that include PC education in undergraduate curricula (ratio of medical schools with PC at undergraduate level/total medical schools). (Here, there would be no differentiation if the course is mandatory or voluntary, if it's an independent course, or what the numbers of hours or specific contents are.)
ED2. Proportion of nursing schools that include PC education in undergraduate curricula (ratio of nursing schools with PC at undergraduate level/total nursing schools)
ED3. Number of specialized PC educational programs for physicians, accredited by the responsible national authority (the absolute number). Specialized PC education is defined as specialty, subspecialty, master, or diploma, as defined by the respective competent authority and includes all formal postgraduate degrees.
Service provision
PS1. Inclusion of PC in the list of services provided in the primary care level (yes = 1; no = 0)
PS2. Number of PC care services per 1 million inhabitants defined according to the Atlas ALCP criteria
PS3. Number of accredited/specialized physicians working in PC per 1 million inhabitants
Medications
ME1. Consumption of strong opioids per cancer death (milligrams per number of deaths)
ME2. Consumption of strong opioids per capita (milligrams per capita)
ME3. Number of pharmaceutical establishments that dispense strong opioids per one million inhabitants

The resolution also instructed WHO to take the necessary steps to provide guidance and support to countries in the implementation of the recommendations.

WHO has put together a task force group of public health and PC experts, which is currently working on developing tools and guidelines for the governments, under the coordination of WHO's secretariat in Geneva. In 2012, the Latin American Association for Palliative Care (ALCP for its Spanish acronym) requested support from the International Association for Hospice and Palliative Care (IAHPC) to jointly develop PC macroindicators that the ALCP could use to monitor and report on the development and progress of PC in the region. A set of ten indicators was developed following the WHO public health model (**Table 1**). An analysis of the development of PC in 27 countries in Latin America using these indicators demonstrated that they are useful for assessing national levels of PC development and that they may be applicable to other world regions (54). These indicators may be helpful to governments as a tool to measure, monitor, and report the level of development, including access to medicine, education, and service provision. The ALCP has proposed the use of these indicators to monitor progress at the country level.

Adequate Policies

The WHA resolution urges member states to develop, strengthen, and implement PC policies; to integrate PC services in a continuum of care across all levels, with an emphasis on primary care; to ensure adequate domestic funding and allocation of human resources for PC, including education and training; and to support the availability and appropriate use of essential medicines, including controlled medicines for symptom management.

Several regions and countries have consistently been identified as role models for adequate PC policies: Australia, Chile, Costa Rica, Ireland, Panama, Romania, Uganda, South Africa, and the Regions of Catalonia and Extremadura in Spain (7, 31, 35). Recent PC policy developments have been reported for several countries, including Albania, Colombia, Mexico, and Panama (18, 42, 48, 51).

International Association for Hospice and Palliative Care (IAHPC): a nonprofit organization dedicated to the worldwide advancement and promotion of palliative care

Medicine Availability and Accessibility

Pain is one of the most feared and most prevalent symptoms in patients with life-limiting conditions, and in the United States, its prevalence has increased over the past decade (62). Opioid analgesics, such as morphine, oxycodone, and hydromorphone, are considered essential medicines by WHO and are included in the WHO Model List of Essential medicines (77) and in the WHO Model List of Essential Medicines for Children for pain (http://www.who.int/medicines/publications/essentialmedicines/EMLc2015_8-May-15.pdf). The essential medicines concept developed by WHO states that there is a list of minimum medicines for a basic health care system, including the most efficacious, safe, and cost-effective ones for priority conditions (74). They satisfy the primary health care needs of the population and so should always be available, affordable, and adequately used. **Figure 2** includes the WHO Model List of Essential Medicines for Palliative Care.

Education

The WHA resolution calls on governments to include PC as an integral component of the ongoing education and training offered to care providers, including basic, intermediate, and specialist training as well as for continuing education for medical and nursing education, health care workers, and caregivers. The resolution emphasizes the need to educate health care professionals working in primary care to ensure that the vast majority of the patients are treated in community centers and in their homes. A recent initiative developed through a consensus-based process developed the core competences for medical and nursing schools in Colombia in six different categories: (a) definition and principles of palliative care, (b) symptom assessment and control, (c) end of life, (d) ethical and legal issues, (e) psychosocial and spiritual issues, and (f) teamwork (55). A report with a summary of the recommendations has been published on the IAHPCC website (39).

Service Provision and Implementation

As PC movement has expanded, there has been increasing evidence of the effectiveness of some aspects of the treatment and care it has promoted. Systematic reviews of the evidence, including studies of people with cancer from many different countries, show consistent findings of the importance of certain key areas of care, which include patients with other illnesses, such as cardiovascular conditions, dementia, renal failure, and neurological conditions (36, 59). The evidence is currently strongest for simple measures, such as pain relief, good communication, and coordinated teamwork to satisfy preferences for place of care. Many patients wish to be cared for and supported until death in the place of their choice, which for the majority of patients (50% to 70%) is their own home (4, 29). A meta-analysis reveals that the control of pain and other symptoms benefits both patients and families (36). Success stories regarding the benefits of community-based palliative care programs are also reported in the literature (41). One well-known case is the State of Kerala, India, where a community model for PC that relies on both volunteers and professionals to provide care for patients and families has been implemented and funded by the state government (**Figure 3**). This program, which started in 2001, was initially volunteer based and delivered spiritual and emotional support and guidance to patients and caregivers. The network relies on 15,000 trained community volunteers to help the few PC physicians and nurses who look after more than 15,000 patients. In 2008, Kerala became the first Indian state to develop a state-sponsored PC policy that included PC as a major component of health care (43).

2. Medicines for pain and palliative care	
2.1 Non-opioids and non-steroidal anti-inflammatory medicines (NSAIMs)	
Acetylsalicylic acid	Suppository: 50 mg to 150 mg Tablet: 100 mg to 500 mg
Ibuprofen [a]	Oral liquid: 200 mg/5ml Tablet: 200 mg; 400 mg; 600 mg [a] Not in children less than 3 months
Paracetamol*	Oral liquid: 125 mg/5 ml Suppository: 100 mg Tablet: 100 mg to 500 mg *Not recommended for anti-inflammatory use due to lack of proven benefit to that effect
2.2 Opioid analgesics	
Codeine	Tablet: 30 mg (phosphate)
Morphine*	Granules (slow-release; to mix with water): 20 mg to 200 mg (morphine sulfate) Injection: 10 mg (morphine hydrochloride or morphine sulfate) in 1-ml ampoule Oral liquid: 10 mg (morphine hydrochloride or morphine sulfate)/5 ml Tablet (immediate release): 10 mg (morphine sulfate) Tablet (slow release): 10 mg to 200 mg (morphine hydrochloride or morphine sulfate) *Alternatives limited to hydromorphone and oxycodone
2.3 Medicines for other common symptoms in palliative care	
Amitriptyline	Tablet: 10 mg; 25 mg; 75 mg
Cyclizine [c]	Injection: 50 mg/ml Tablet: 50 mg
Dexamethasone	Injection: 4 mg/ml in 1-ml ampoule (as disodium phosphate salt) Oral liquid: 2 mg/5 ml Tablet: 2 mg [c]; 4 mg
Diazepam	Injection: 5 mg/ml Oral liquid: 2 mg/5 ml Rectal solution: 2.5 mg; 5 mg; 10 mg Tablet: 5 mg; 10 mg
Docusate sodium	Capsule: 100 mg Oral liquid: 50 mg/5 ml
Fluoxetine [a]	Solid oral dosage form: 20 mg (as hydrochloride) [a] > 8 years
Haloperidol	Injection: 5 mg in 1-ml ampoule Oral liquid: 2 mg/ml Solid oral dosage form: 0.5 mg; 2 mg; 5 mg
Hyoscine-butylbromide	Injection: 20 mg/ml
Hyoscine hydrobromide [c]	Injection: 400 micrograms/ml; 600 micrograms/ml Transdermal patches: 1 mg/72 hours
Lactulose [c]	Oral liquid: 3.1–3.7 g/5 ml
Loperamide	Solid oral dosage form: 2 mg
Metoclopramide	Injection: 5 mg (hydrochloride)/ml in 2-ml ampoule Oral liquid: 5 mg/5 ml Solid oral dosage form: 10 mg (hydrochloride)
Midazolam	Injection: 1 mg/ml; 5 mg/ml Oral liquid: 2 mg/ml [c] Solid oral dosage form: 7.5 mg; 15 mg
Ondansetron [c] [a]	Injection: 2-mg base/ml in 2-ml ampoule (as hydrochloride) Oral liquid: 4 mg base/5 ml Solid oral dosage form: Eq 4 mg base; Eq 8 mg base [a] > 1 month
Senna	Oral liquid: 7.5 mg/5 ml

Figure 2

List of essential medicines for palliative care included in the WHO Model List of Essential Medicines. The [a] symbol indicates that there is an age or weight restriction on use of the medicine; details for each medicine can be found in **Table 1**. The [c] symbol placed next to an individual medicine or strength of medicine signifies that there is a specific indication for restricting its use to children.



Figure 3

Visit to a patient in the community palliative care program in India. Photo of Dr. M.R. Rajagopal, director of Pallium India in Kerala, giving instructions to Nurse Sherin on the medications needed for the patient he just visited. Photo credit: Dr. Eric Krakauer. Used with permission.

THE WAY FORWARD

Success in the improving care of the dying depends on the ability to overcome the barriers that remain in implementing and adopting the components of the WHO public health model for PC: policy, education, medicine, and service provisions (19). In the United States, the main challenges in the adoption of hospice care have been identified in the literature as constraints in public policy (especially the Medicare hospice benefit), limited health insurance, the negative attitudes and practices of health care providers, and the attitudes and preferences of health care consumers and the public toward death and dying (40).

Data indicate that PHS offers the best approach for translating new knowledge and skills into evidence-based, cost-effective interventions that can reach all the patients in need (47). Public

health provides health information and resources to individuals, health care providers, and professionals on a broad range of issues from sanitation and immunizations to community-based self-management programs. In an age of relatively easy access to vast amounts of information, public health has particular strengths as an objective, evidence-based information source. For PHSs to be effective, they must be incorporated by governments into all levels of their health care systems, sharing ownership with the community. Health-promoting PC translates the ideals of whole-person care into broader public health language and practices related to prevention, harm reduction, support, education, and community action. Some of the recommended strategies in the literature include the following:

1. Incorporate PC education at undergraduate levels to meet the increasing demand for home care PC services. Recommendations for primary health care reform to ensure the quality of the health sector should also include creating human resource development plans at the village, district, state/regional, and national levels and strategies for retention of trained personnel in remote and rural areas (47). In order for this to be effective, authors state there is a need to develop a care model that distinguishes primary PC (skills that all clinicians should have) from specialist PC (skills for managing more complex and difficult cases) so that primary care physicians can continue caring for patients at home (71). Studies suggest that most people with advanced illnesses prefer to be cared for at home or near their home, but most people die in institutions or, if at home, without the appropriate care (30). These plus several other limitations call for the identification of priorities in the delivery of primary palliative care, so that the health care providers are able to meet the most pressing needs of patients with advanced life-limiting conditions and those of their families. In 2012, IAHPC developed, through a consensus-based process, a List of Essential Practices in Palliative Care, which should be provided to physicians, nurses, and nurse aides working at the primary care level; these are applicable in all socioeconomic settings and include those practices aimed at meeting the most prevalent physical, social, psychological, and spiritual needs of palliative care patients and their families (23).
2. Engage the community in participating in a shared decision model, identify and plan for their preferred ways of care, and integrate the knowledge obtained from the community and caregivers in the community health care plan (67). There is a wealth of knowledge and experience among caregivers, and their expertise in caring and coping strategies, loss, and grief can be used and applied in such a model.
3. Develop a communications strategy to disseminate culturally appropriate materials about advance care planning to insurance, health care providers, and the public before patients and family members have to make EOL decisions. Public health officials can encourage open discussions about EOL preferences among patients, family members, and the health care providers to ensure that there is better understanding of the benefits of hospice and palliative care.
4. Develop local PC leaders in low- and middle-income countries who can implement palliative care services, engage with their governments, provide expert advice to lawmakers, and act as a bridge with national and international organizations and local resources. The International Leadership Development Initiative developed and implemented, over a five year period, two leadership courses for 39 emerging palliative care physician leaders from 25 countries. Reports from graduates of this program indicate that they have been successful on several fronts, including developing national policies, improving availability of opioids, and changing the curricula in their medical schools (60).

CONCLUSIONS

For a multitude of reasons, PC is an important health issue and represents an effective approach to minimize the burden of illness and costs to the community, suffers from inequities in access, and is set to be a major health concern for the future. The WHA resolution presents an extraordinary opportunity for the advancement of palliative care in the world: The resolution outlines clear recommendations to the United Nations member states, such as including PC in all national health policies and budgets as well as in the undergraduate curricula for health care professionals, and highlights the critical need for countries to ensure that there is an adequate supply of essential PC medicines, especially those needed to alleviate pain. This resolution carries great challenges as well because global access is grossly inequitable.

PC implementation has demonstrated efficacy in the care of the patients and families, efficiency in the provision of care, and cost benefits in the global health care approaches. It adds qualitative and organizational values to the health care system. Its implementation must be prioritized and planned by the health administrators as a priority public health issue, not only to improve the global efficiency and appropriate use of resources in the system but also to improve the quality of care for patients with life-limiting illnesses and to relieve suffering.

SUMMARY POINTS

1. An estimated 40 million people are in need of palliative care worldwide, and of these, 6% are children. Most (80%) of people in need of palliative care live in low- and middle-income countries, where access to palliative care is limited.
2. The unmet need for palliative care results in pain and suffering for millions of adults and children each year. Worldwide, only one in ten people who need palliative care receive it.
3. In 2011, 75% of the population in the world (5.5 billion people) lived in countries where access to pain relief was limited or nonexistent.
4. Unduly restrictive laws and regulations for the use of controlled medications, such as morphine and other opioids, are a major barrier to accessing adequate pain relief and palliative care in many countries in the world.
5. In the United States, the main challenges in the adoption of hospice and palliative care are constraints in public policy, limited health insurance coverage, the negative attitudes and practices of health care providers, and the attitudes and preferences of health care consumers and the public toward death and dying.
6. Palliative care improves the quality of life by addressing the physical, psychosocial, and emotional suffering of patients with life-limiting illnesses and conditions.
7. Palliative care is a public health issue: It needs to be provided in accordance with the principles of universal coverage and should be integrated in health laws, health system policies, and all relevant global disease control plans.
8. In 2014, WHA unanimously approved a resolution that provides clear recommendations to the United Nations member states, such as including palliative care in national health policies and in the undergraduate curricula for health care professionals, and highlights the critical need for countries to ensure that there is an adequate supply of essential medicines for palliative care, especially to alleviate pain.

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