

Special Article**The Public Health Strategy for Palliative Care**

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Abstract

The quality of life of at least 100 million people would have improved—if today's knowledge of palliative care was accessible to everyone. A Public Health Strategy (PHS) offers the best approach for translating new knowledge and skills into evidence-based, cost-effective interventions that can reach everyone in the population. For PHSs to be effective, they must be incorporated by governments into all levels of their health care systems and owned by the community. This strategy will be most effective if it involves the society through collective and social action. The World Health Organization (WHO) pioneered a PHS for integrating palliative care into a country's health care system. It included advice and guidelines to governments on priorities and how to implement both national palliative care programs and national cancer control programs where palliative care will be one of the four key pillars of comprehensive cancer control. The WHO PHS addresses 1) appropriate policies; 2) adequate drug availability; 3) education of policy makers, health care workers, and the public; and 4) implementation of palliative care services at all levels throughout the society. This approach has demonstrated that it provides an effective strategy for integrating/establishing palliative care into a country. J Pain Symptom Manage 2007;33:486–493. © 2007 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

Key Words

Public health, policy, drug availability, education, implementation, palliative care

Why a Public Health Strategy?

Palliative care relieves suffering and improves quality of life for both patients and families throughout an illness experience, not just at the end of life.¹ Today, there is the knowledge to relieve much of the unnecessary

suffering. Tragically, however, palliative care is only reaching a fraction of the people who need it.

A Public Health Strategy (PHS) offers the best approach for translating new knowledge and skills into evidence-based, cost-effective interventions that can reach everyone in the population. For public health strategies to be effective, they must be incorporated by governments into all levels of their health care systems and owned by the community. This strategy will be most effective if it involves the society through collective and social action.

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The Need for Palliative Care

Globally, there is a very significant unmet need for palliative care:

- Of the 58 million people dying annually (45 million in developing countries, 13 million in developed countries), it is estimated that at least 60% (35 million) will have a prolonged advanced illness and dying and would benefit from palliative care.²
- Already, there are 600 million people 60 years of age or older.
- With at least two family members involved in each patient's care, palliative care could improve the quality of life of more than 100 million people annually worldwide.

Palliative care is particularly important for patients with cancer and AIDS, as the burden of issues that cause suffering is particularly high for these patients:

- Two-thirds (seven million) of the 10 million new patients with cancer each year are not cured and die within a year of their diagnosis.
- Of those living with cancer, 60% will experience significant pain.
- Already, three million patients die annually from AIDS.

With the rapidly aging world population and the associated increase of multiple "noncommunicable" diseases, the need for palliative care will increase dramatically over the next 50 years.^{3,4}

- By 2025 there will be 1,200 million people 60 years of age or older; by 2050 the number will increase to 2,000 million.
- The incidence of cancer will more than double to an estimated incidence of 24 million new cancers per year by 2050.
- If preventative measures don't work, annual mortality from AIDS will increase to four million in 2015 and six million by 2030.

Throughout the world, many patients present late to their health care system with advanced disease. Therapies to control their disease are frequently ineffective, associated with multiple side effects that cause increased suffering and are expensive. For these patients, palliative care, if available, would give the greatest benefit during their limited life expectancy,

for the least cost.⁵ Even in the developed world, when patients present earlier to the health care system and there is a greater chance that their disease is curable, a comprehensive approach to their care that integrates palliative care throughout their illness experience will provide them with better quality of life.

Unfortunately, although the knowledge and experience to control pain and diminish suffering exist, the tragedy for most of the world's population is that palliative care is not available to them. In fact, the greatest need is in developing countries, where 45 million of the deaths occur and health care resources are the scarcest.

A Public Health Approach

A public health approach aims to protect and improve the health and quality of life of a community by translating new knowledge and skills into evidence-based, cost-effective interventions that will be available to everyone in the population who needs them. As palliative care is an integral part of care for all patients, and the most beneficial approach to care for patients with advanced disease, it is important that all countries integrate pain relief and palliative care into their health care systems at all levels.⁶⁻¹²

A WHO Public Health Model

In 1990, the WHO pioneered a PHS to integrate palliative care into existing health care systems. This included advice and guidelines to governments on priorities and how to implement national palliative care programs and national cancer control programs where palliative care will be one of the four key components (pillars) of comprehensive cancer care.^{4,13}

Based on experience with this model and the process to implement it, an enhanced Public Health Model (the Model) has emerged (Fig. 1).

To effectively integrate palliative care into a society and change the experience of patients and families, all four components of the WHO Public Health Model must be addressed. There must be 1) appropriate policies, 2) adequate drug availability, 3) education of health care workers and the public, and 4) implementation

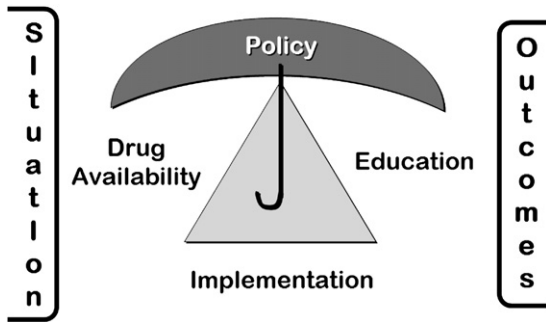


Fig. 1. WHO Public Health Model.

of palliative care services at all levels throughout the society. This process is always implemented within the context of the culture, disease demographics, socioeconomic, and the health care system of the country. For each component there are short, intermediate, and long-term outcomes that must be measured.¹⁴

Developmental Steps

Step 1: Engage Opinion Leaders

Start by gaining access to key governmental and nongovernmental opinion leaders for the country. An ideal way (for external international experts) to access these leaders is a combined approach in collaboration with the Minister of Health and local/regional WHO representatives.

Step 2: Situational Analysis

After engaging with national opinion leaders, perform an analysis of the situation and needs within the country (Table 1).

Step 3: Develop an Action Plan

After completing the situational analysis, the next step is a workshop of key national political and clinical opinion leaders, nongovernmental organizations, and international expert facilitators.^{12,14–17}

Based on the results of the detailed situational analysis and needs assessment, the goal of this national workshop is to produce a consensus-based report and action plan with a timeline for addressing each of the four components of the model and outcome indicators for each component (review a sample report and action plan online¹⁸).

Step 4: Establish a National Steering Committee

Once an action plan is in place, establish a national steering committee of key stakeholders to coordinate the overall process in collaboration with international expert facilitators. This committee is typically chosen from workshop participants and includes key politicians, regulators, clinicians, educators, administrators, and the public.

Step 5: Develop the Components of the Model

Details of the model are presented in Fig. 2. Before embarking on extensive education and implementation strategies, ensure that policies and drug availability issues are addressed and are in place. These are inextricably linked as it is not realistic to import opioids unless appropriate prescription rules are in place and bedside-training courses can be guaranteed. Do not embark on training without appropriate

Table 1
Situational Analysis

Population Statistics	Health Care System	
Disease demographics <ul style="list-style-type: none"> • Mortality rates • % Patients presenting with advanced-stage disease 	<ul style="list-style-type: none"> • Policies and regulations—whether they include pain relief and palliative care as priorities • Acute, home and long-term care services • Manpower training and distribution • Funding of health care delivery systems, health care personnel (e.g., doctors, nurses, pharmacists, and social workers), medications and therapies, equipment, and supplies 	
Socioeconomic statistics <ul style="list-style-type: none"> • Social and family structure • Income levels • Religions 		
Community resources <ul style="list-style-type: none"> • Nongovernmental organizations • Community activists • Social action networks 		
		Medication usage <ul style="list-style-type: none"> • Opioid and essential medicine availability¹⁵ • Associated costs, compared with incomes • Laws and regulations governing prescription • Opioid quota, usage • Who manages the quota; what process is used to review the quota annually and request a new quota from INCB • How are opioids distributed, dispensed, and accounted for

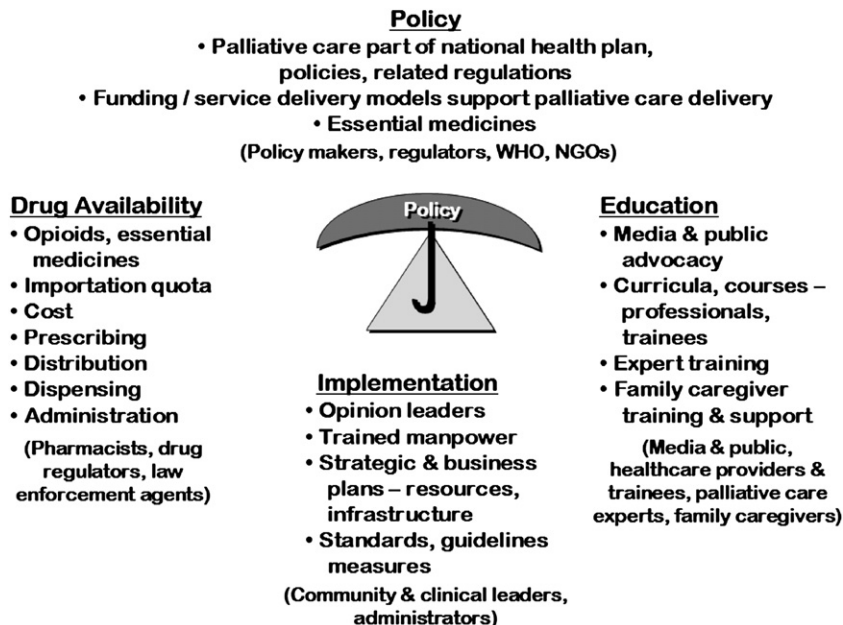


Fig. 2. Detailed WHO Public Health Model.

policies and drug availability. It will only frustrate clinicians, patients and families, and the public.

Policy

Start by identifying key policy stakeholders. These frequently include both national and regional government policy makers and regulators.

Review national health policies and related regulations to establish whether they incorporate the relief of pain and palliative care as priorities. If they do not, advocate for incorporation of both of these concepts as priorities into the National Health Plan, legislation, and regulations as they evolve.

Review existing funding and service delivery models for providing care within the country. Determine how they might support the delivery of palliative care both at the community level and within existing acute and long-term care organizations through home care and consult services, and palliative care units. Review how doctors and other health care professionals providing palliative care are reimbursed.

Establish if the country has an essential medicines policy. If they do, include opioids and other palliative care medicines in the policy.

Drug Availability

Identify Leaders. Start by identifying national opinion leaders responsible for drug availability, e.g., drug regulators, pharmacologists, pharmacists, and law enforcement officials. Ensure that they are all engaged in the process and willing to review and improve drug availability policies and practices.

Estimate Opioid Need. Use a simple strategy to estimate the annual opioid need for the cancer patients. Assume that 60% of patients with advanced cancer will be the principal consumers and that they will each use an average of 100 mg morphine per day for the last 100 days (three months) of their lives, i.e., a total of 10 g of morphine per patient. This technique will estimate only a portion of the total opioid need for the country. As an example, for a country with five million people and 3,500 new diagnoses of cancer per year, two-thirds of which present with stage III or IV cancer, if 60% of these patients (2,100) have pain and need 10 g of morphine each before they die, that country will need 21 kg of morphine per year just to manage these cancer patients' pain.

Ensure an Affordable Supply. Request a reasonable opioid quota from the International Narcotics Control Board (INCB) well before it is needed. Base this request on the previous years' actual usage and a reasonable estimate of increased usage for the coming year. As long as there is a timely system to review usage and the available supplies, if consumption exceeds the request quota, a revised request for an increased quota can always be submitted to the INCB during the year.

Ensure that there is a national policy to guide the importation of affordable, "equally efficient" generic morphine and other opioid formulations. Most patients' pain will be easily managed if the country ensures that they have a supply that includes 30% immediate-release morphine, 60% slow-release morphine, 5% parenteral morphine, and 5% other opioids.^{18,19} To date, the least expensive formulation is oral morphine solution.¹²

Establish an appropriate distribution, dispensing, and accountability system based on the eight steps developed by WHO and INCB.²⁰ To minimize the burden for patients and families, opioids will need to be available in the communities where patients receive their care, not just in a single pharmacy in the country's capital city, e.g., in the National Cancer Center.

Facilitate Appropriate Prescribing. Ensure that opioid prescribing laws and regulations allow the appropriate management of pain and shortness of breath. All doctors, in any setting, should be able to prescribe the quantity that will be required for a reasonable period of time.

Education

Identify Leaders. Start by identifying national opinion leaders responsible for education, e.g., clinical and education experts, deans of medical, nursing, pharmacy, and social work schools. Ensure that they are all engaged in the process and willing to change existing educational curricula and courses and develop new ones.

Identify Target Audiences. To implement palliative care effectively across the country, there will be many different target audiences who

will require education to increase their awareness and change their attitudes, knowledge, and skills related to palliative care. Typically these include the media and public, medical, nursing, social work/psychology, and pharmacy health care professionals and trainees, experts training in palliative care, spiritual leaders, and patients and families.

Media and Public Advocacy. Develop an educational intervention and advocacy tools to engage the media and heighten public awareness of the need for and benefits of palliative care for patients at any time during an illness experience.

Curricula, Courses. Education in health care is intended to change the experience of illness for patients and families. To this end, educational interventions increase awareness, change attitudes, increase knowledge and skills, and change behaviors most effectively if courses and conferences are accompanied by bedside training during which students are mentored by skilled palliative care practitioners.²¹ Incorporate the core competencies of palliative care into undergraduate and postgraduate curricula and continuing education courses for practicing professionals.

To facilitate uptake of palliative care education and highlight its importance, include questions on palliative care in undergraduate and postgraduate examinations that are required for certification and licensure.

Palliative Care Experts. Develop a specialized program to train and recognize palliative care experts who will staff the national centers of excellence and provide consultation, education, and support to primary and secondary level practitioners. At the outset, this may need to include out-of-country education of selected individuals to develop their expertise. With time, as sufficient palliative care experts are available locally, these specialized training programs can be developed in country.

Family Caregivers. As patients will primarily receive their care from family members and friends, develop educational interventions and tools to enhance the knowledge and skills of family caregivers.

Implementation of Palliative Care Services

Identify Leaders. Start by identifying one or more community and/or health care organizations that have the potential to become centers of excellence in palliative care based on their leadership potential, the patient population they are caring for, and their commitment to integrate palliative care into the community they serve.

Engage with community, clinical, and administrative leaders within the selected organizations. Help them to see the need for palliative care for their patients and families and how palliative care will help optimize their resource utilization and increase the quality of life and satisfaction of patients and families they are caring for.

Develop a Plan. Once the leadership has agreed to focus on implementing palliative care, help them develop strategic and business plans that incorporate adequate resources and an infrastructure to support the newly evolving program.

Palliative Care for All. Although palliative care services may start in one or more health care organizations that will become centers of palliative care excellence, it is always important to keep in mind the vision that the process to implement palliative care within a country is striving to integrate palliative care into all levels of the society—from the community level upward and from the palliative care expert in the health care system downward (Fig. 3). It will be impossible to develop a palliative care system that is separate from the existing health care system and social support network—there is simply not the capacity to do this. It will be critical for all palliative care experts to spend 40%–50% of their time educating and supporting other health care professionals and community support systems, in addition to providing consultation and direct patient/family care. The Neighborhood Network in Palliative Care Initiative in Kerala, India (a WHO Demonstration Project) demonstrates how to achieve meaningful palliative care coverage for everyone when citizens themselves take responsibility and ownership for community members with advanced illnesses

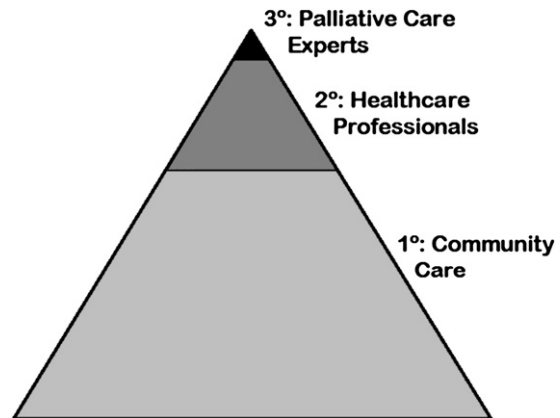


Fig. 3. “Palliative Care for All.”

and the dying. By creating a movement within the community that embraced the existing community support and health care systems, the community integrated “palliative care for all” through a system that came “from the people, for the people, by the people.”^{22–24}

Outcomes

At each step in the process to integrate palliative care into a country, there are fundamental immediate, intermediate, and long-term outcomes that can be monitored by those facilitating the process.

Immediate Outcomes

- Opinion leaders identified—policy makers, regulators, clinicians, administrators.
- Needs and situational analysis completed.
- Action plan and timeline developed.
- Centers of excellence in palliative care identified, e.g., in cancer centers and community support services.
- Outcome indicators identified.

Intermediate and Long-term Outcomes

The intermediate and long-term outcomes are listed in Table 2.

Summary

Millions of patients around the world are experiencing unnecessary suffering and dying without access to palliative care. In light of

Table 2
Intermediate and Long-Term Outcomes

	Intermediate Outcomes	Long-Term Outcomes
Policy	<p>Policies and regulations incorporate pain relief and palliative care as priorities</p> <p>National Health Plan</p> <p>National Cancer Control Policy; National AIDS Policy; National Geriatric Policy, etc.</p> <p>National Palliative Care Policy</p> <p>Funding and service delivery models established to support the provision of palliative care in all settings where patients receive care</p> <p>Funding for health care professionals providing palliative care established</p>	<p>National policies and regulations support palliative care delivery</p> <p>National Palliative Care Policy fully implemented</p> <p>Multiple NGOs and health care organizations incorporate palliative care into their strategies</p> <p>Palliative care services are adequately funded</p> <p>Palliative care professionals and community support workers are adequately funded</p>
Drug availability	<p>Opioid prescribing laws and regulations support pain relief and palliative care</p> <p>Supplies of affordable medications are adequate:</p> <p>Generic opioids—immediate, slow release, and injectable morphine</p> <p>Opioid quota increased</p> <p>Essential medicines</p>	<p>Doctors prescribe opioids to meet patient needs</p> <p>Opioid and essential medications available in adequate supply in community pharmacies</p> <p>Opioid quota and consumption increased</p>
Education	<p>Media and public awareness campaign underway</p> <p>Educational courses underway to provide:</p> <p>Core knowledge and skills to many practicing health care professionals</p> <p>Expert knowledge and skills to a few selected health care professionals who will lead palliative care services</p> <p>Education in palliative care in health care professional training programs</p> <p>Medical, nursing, pharmacy, social work schools</p>	<p>Increased media, public, and health professional awareness of palliative care</p> <p>A large number of health care professionals have core palliative care knowledge and skills</p> <p>A significant number of palliative care experts are in practice</p> <p>All health care trainees and newly licensed professionals have core palliative care knowledge and skills</p>
Implementation	<p>National Palliative Care Plan initiated</p> <p>Palliative care services functional in Centers of Excellence</p> <p>Palliative care services started in health care and community service organizations, e.g., cancer centers, community service organizations</p> <p>National and organizational quality strategies implemented</p>	<p>Communities own and support palliative care services</p> <p>Good coverage, i.e., >80% of the patients in need received palliative care</p> <p>Quality of life is improved for patients and families (as identified by selected clinical outcome measures)</p> <p>National model, standards, guidelines, outcome measures guide palliative care practice</p> <p>Benchmarking/accreditation process is underway to compare and improve palliative care services</p>

the new knowledge and the skills that we now have to manage the suffering and ensure safe and comfortable dying, this is a major public health issue worldwide. The enhanced WHO Public Health Model has demonstrated that it provides an effective strategy for integrating palliative care into a country. By customizing the process for the situation in each country, addressing all of the elements in the strategy, implementing quality palliative care services, and realizing all of the planned outcomes, population-based coverage will be assured. The final outcome will be adequate relief of suffering and improvement of quality of life

for all patients living with advancing illness and their families.

References

1. WHO Definition of Palliative Care. Available from <http://www.who.int/cancer/palliative/definition/en>.
2. Stjernsward J, Clark D. Palliative medicine—a global perspective. In: Doyle D, Hanks G, Cherny N, Calman K, eds. Oxford textbook of palliative medicine, 3rd ed. Oxford: Oxford University Press, 2004:1197–1224.

3. Incidence and mortality data. Available from www.who.int/whr/2003/en/annex2-en.pdf.
4. World Health Organization. Cancer pain relief and palliative care. Technical report series 804. Geneva: World Health Organization, 1990. Available from <http://www.who.int/cancer/publications/en>.
5. Gomez-Batiste X, Porta J, Tuca A, et al. Spain: The WHO demonstration project of palliative care implementation in Catalonia: results at 10 years (1991–2001). *J Pain Symptom Manage* 2002;24:239–244.
6. Stjernswärd J, Stanley K, Tsechkovski M. Cancer pain relief: an urgent public health problem in India. *Indian J Pain* 1985;1:95–97.
7. Stjernswärd J. WHO cancer pain relief programme. *Cancer Surv* 1988;7:196–208.
8. Stjernswärd J, Colleau S, Ventafridda V. The World Health Organization cancer pain and palliative care program: past, present and future. *J Pain Symptom Manage* 1996;12(2):65–72.
9. Stjernswärd J, Pampallona S. Palliative medicine—a global perspective. In: Doyle D, Hanks G, MacDonald N, eds. *Oxford textbook of palliative medicine*, 2nd ed. Oxford: Oxford Medical Publications, 1997:1225–1245.
10. Singer P, Bowman K. Quality end-of-life care: a global perspective. *BMC Palliat Care* 2002;1(1):4.
11. Foley KM. How much palliative care do we need? *Eur J Pall Care* 2003;10(2):5–7.
12. Stjernswärd J. Uganda: initiating a government public health approach to pain relief and palliative care. *J Pain Symptom Manage* 2002;24(2):257–264.
13. World Health Organization. National cancer control programs: Policies and managerial guidelines. Geneva: World Health Organization CAN/92.1, 1993 and 1995.
14. Stjernswärd J, Gomez-Baptiste X. Palliative care: The public health strategy. *J Public Health Policy* 2007;28:42–55.
15. WHO essential medicines. Available from <http://mednet3.who.int/EMlib/index.aspx>.
16. Davaasuren O, Stjernswärd J, Callaway M, et al. Mongolia: establishing a national palliative care program. *J Pain Symptom Manage* 2007;33:568–572.
17. Stjernswärd J, Ferris FD, Khleif SN, et al. Jordan palliative care initiative: a WHO demonstration project. *J Pain Symptom Manage* 2007;33:628–633.
18. Stjernswärd J. National palliative care program. Tbilisi, Georgia: Georgian Parliament. Available from www.parliament.ge/files/619_8111_336972_Paliativi-Eng.pdf.
19. Ministry of Health Order Development of palliative care 2006–2009. Ulaanbaatar, Mongolia. 246, 2005.
20. World Health Organization. Cancer pain relief with a guide to opioid availability. Geneva: World Health Organization, 1996. Available from <http://www.who.int/cancer/publications/en>.
21. Ferris FD, von Gunten CF, Emanuel LL. Knowledge: insufficient for change. *J Palliat Med* 2001;4(2):145–147.
22. Stjernswärd J. Community participation in palliative care. *Indian J Palliat Care* 2005;11(2):111–117.
23. Kumar S. The chronically and incurably ill: barriers to care. In: *The commonwealth ministers reference book*. Bradford, UK: The University of Bradford Press, 2006:2–5.
24. Kumar S, Numpeli M. Neighborhood network in palliative care. *Indian J Palliat Care* 2005;11:6–9.