

EASING THE PAIN

SUCCESSES AND CHALLENGES IN INTERNATIONAL PALLIATIVE CARE



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International Palliative Care Initiative
Public Health Program



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We would like to thank the individuals who are featured throughout this book. You are our champions for palliative care.

In addition, we would like to thank the national foundations for their commitment in advancing palliative care.

A Letter from the Directors

For the past decade, advancing palliative care globally has been the major goal of the Open Society Foundations International Palliative Care Initiative. In the late 1990s, several of our regional foundations worldwide expressed interest in addressing issues involving the care of seriously ill and dying patients. The International Palliative Care Initiative uses a targeted, multi-pronged, public health approach to advance the following priorities: reform health policy; make available essential medicines for pain relief and palliative care; educate health care professionals and policy makers; and raise public awareness about palliative care and the rights of patients and families. The Initiative's budget, which began with \$500,000, is now at \$2.6 million dollars a year.

This publication highlights the work of only a small number of our grantees and their progress in creating a new field of care.

As a funder, we have tried to be catalytic and collaborative and we are indebted to a wide range of funders, both governmental and nongovernmental, who have helped to champion the need

for palliative care for all. Our partnerships with the International Atomic Energy Agency, World Health Organization, and the International Network for Cancer Research and Therapy to develop six regional cancer centers of excellence have helped focus global attention on the enormous need for palliative care, especially for cancer patients. Likewise, the National Cancer Institute's support is nurturing palliative care champions through international fellowships, sensitization workshops, and a leadership development program. Our work and the work of our grantees with the U.S. President's Emergency Plan for AIDS Relief, the UK Department for International Development, the UN Commission on Narcotic Drugs, and the International Narcotics Control Board have elevated the problem of inadequate access to essential medicines for palliative care onto the global health agenda. Funders such as The Diana, Princess of Wales Fund, Hope Hospice, the Foundation for Hospices in Sub-Saharan Africa/National Hospice Palliative Care Organization, The Elton John AIDS Foundation, True Colours Trust, and many other national and international donors have enhanced our work and helped to get palliative care on the global donor agenda.

The Open Society Foundations continue to position pain relief and palliative care as a pressing human rights issue. Through grants and technical assistance, we help to create links between legal services and palliative care providers. We work with our grantees to evaluate financing schemes for palliative care and help them develop advocacy and communications strategies to advance palliative care policies and programs. We work with the Global Fund to Fight AIDS, Tuberculosis and Malaria to educate staff, country partners, and grant recipients about the role of and need for palliative care in AIDS treatment.

The International Palliative Care Initiative's strategy of "planting a seed to let a thousand flowers grow" has enhanced the development of palliative care in resource-limited countries worldwide. The challenges ahead are many but the dedication of individuals and civil society organizations to reduce suffering and improve the care of patients and families remains inspirational.

This report offers a snapshot of the challenges and opportunities for advancing palliative care globally. We also hope to inspire potential partners, donors, and advocates by sharing a few stories of some of the amazing individuals and organizations working to relieve the suffering of millions of people around the world.

Kathleen Foley, MD
*Medical Director
International Palliative
Care Initiative*

Mary Callaway
*Project Director
International Palliative
Care Initiative*



IPCI Project Director Mary Callaway with a nurse in the township of Soweto in South Africa

Introduction

In Medieval times, when travelers fell ill, they could find refuge in monastery “hospices”—a word from the Latin *hospes*, meaning “to host a guest or stranger”—sometimes staying until their final hour, ministered to by monks, nuns, and laywomen.

But in 2002, it was the caregivers who were traveling, down a red dirt road through the banana plantations of Masaka District, Uganda. The travelers were local palliative care workers, including Faith Mwangi-Powell, director of the African Palliative Care Association (APCA), and they were on their way to the grass-thatched mud house of Mary, a seven-year-old HIV-positive orphan, and her 80-year-old paraplegic grandmother. Mary and her granny had been discovered four months earlier by a businessman in the area buying bananas and were now receiving fortnightly visits from a nurse. This time, the nurse gave Mary her medicine, then knelt beside the grandmother to examine her bedsores and administer pain killers. Before leaving, the nurse put aside a supply to last until the next time. She also gave the two patients some food. Neither had eaten for three days.

Mwangi-Powell felt awkward in the humble house, like an intruder in a tragedy that was being repeated throughout sub-Saharan Africa. “But the grandmother asked me, ‘Why are you so upset?’” she recalls. “She told me not to be upset. She said, ‘I am really happy because every other week, a nurse comes

and gives me medicine for my pain and cares for my granddaughter. I wish they had come three years ago. I am enjoying this now, even though I don’t have much time to live. Now I can die knowing that people know I exist.” The woman and the girl rewarded their visitors with broad, if weak, smiles.

As the group left the village, they noticed it was spotted with the graves of people who had died of AIDS. Still, Mwangi-Powell noted, “That woman made me see palliative care in a very different light. If she dies now, she felt it is fine. Because all her children had died, there was no one to know she exists. Now someone knows she exists. We are making a real difference.”

Why Palliative Care?

The answer, so poignantly evoked in this story, is *pain*. This family’s pain was what Dame Cicely Saunders, the modern hospice movement’s founder, called “total pain,” the combination of “physical, spiritual, psychological, and social pain” that must be attended to in people who are being treated for life-limiting illnesses or who are dying. The breadth of the definition of total pain expands further in the developing world, where it often includes poverty, hunger, dislocation, and violence.

Palliative care treats total pain by treating the total person. “You matter because you are you, and you matter until the last moment of your life,” said Dame Saunders. “We will do all we can, not only to help you die peacefully, but also to live until you die.” This is the message an old, almost-forgotten Ugandan woman received from the caregivers visiting her hut: She matters. She “exists.”

Illness and death are facts of life, but suffering need not be. This is the reason for palliative care. It is the reason the Open Society Foundations Public Health Program launched its International Palliative Care Initiative (IPCI) in 1999. IPCI supports resource-limited countries in integrating palliative care into their national health care policies, budgets, delivery systems, and into professional and public education. Central to these efforts is ensuring that essential medications for pain and symptom relief are available to everyone who needs them.

In the generosity of its funding, the intelligence of its strategy, and the excellence of its technical support, IPCI is recognized as a leading catalyst to action and support for ongoing development, a crucial player in the worldwide movement for palliative care.

What is Palliative Care?

Derived from the Latin *palliare*, “to cloak,” palliative care is a form of medical care or treatment that seeks to ease the severity of disease symptoms, whether or not a cure is possible (palliative care includes *hospice care* which delivers such care at the end of life). According to the World Health Organization (WHO), palliative care is an approach that improves the quality

of life of patients and their families facing the problem 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 physical, psychosocial, and spiritual problems. Palliative care:

- 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;
- helps the patient’s 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;
- will enhance quality of life, and may also positively influence the course of illness;
- 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, antiretrovirals or antibiotics and includes those investigations needed to better understand and manage distressing clinical complications.

A Great Need, Unevenly Met

The need for palliative care is great and growing. Fifty-eight million people die annually—45 million in developing countries. Of these it is estimated that at least 60 percent, or 35 million, will have a prolonged advanced illness before dying and would benefit from palliative care.¹ In the developing world, where preventive medicine and good medical care are scarce, two illnesses account for the lion's share of pain and mortality among both adults and children: cancer and AIDS. Usually diagnosed too late for meaningful curative treatment, palliative care is the humane, affordable answer.

- In spite of falling life expectancies in countries plagued by HIV/AIDS, the world's population is aging. Today 600 million people are over 60; by 2050, the aged will comprise two billion. Most of this increase is occurring in developing countries, where the number of older people is expected to rise to 1.7 billion by 2050.²
- Of the 10 million new cases of cancer per year, at least two-thirds are not cured, and death comes within a year of diagnosis. Incidence projections put new cases at 24 million yearly by 2050. Among those living with advanced cancer, 60 to 90 percent experience moderate to severe pain.³
- In 2007, three million patients were dying annually from AIDS. If preventive measures do not work, annual mortality from AIDS will grow to four million by 2015, six million by 2030. Researchers report that up to 80 percent of patients in the final stage of the illness experience significant pain.⁴
- In Africa alone, 520,000 children died of HIV/AIDS in 2006—one every minute.⁵

Palliative care can relieve suffering—but that effect is not limited to the patient. Add at least two family caregivers to each ill or dying person and palliative care could improve the quality of life for over 100 million people worldwide right now.

Life, Death, and Poverty

In only 40 years, modern palliative care has made remarkable progress. Of the 234 countries monitored by the International Observatory on End of Life Care (IOELC) at Lancaster University in England, half have instituted some kind of palliative care program. But it has a long way to go. Only 35 countries, or 15 percent of the total, have come far enough to be included in the IOELC's highest category, "Approaching Integration." Seventy-eight countries—a third—are categorized as having "no known activity" at all.⁶

The per-capita consumption of opioid analgesics—the core medicine of pain and symptom management and thus a good gross indicator of palliative care development—offers another picture of global inequity. According to data from the International Narcotics Control Board (INCB), which collects opioid consumption rates from the mandatory annual reports of national governments, of the 27 million grams of morphine used legally in 2002, 78 percent went to six high-income countries: Australia, Canada, France, Germany, United Kingdom, and United States. The rest was shared among the other 142 reporting countries.

The campaign for palliative care in resource-limited countries does not represent a cynical resignation to the mass death of the poor, because palliative care is not a substitute for active treatment. It is an adjunct to it. Analgesics are as basic to the

“This is What We Live With Now”

“In resource-limited countries, most people present with cancer at advanced stages. They have multiple symptoms; their disease is incurable. What do you do for those patients? WHO has argued that palliative care is an essential part of a minimum package of health care. That means pain and symptom management, psychological support, and bereavement counseling.

“There’s been an argument that by spending your time and money doing palliative care, you are not preventing cancer or AIDS. It’s an argument. But the answer is: This is what we live with now. The impact of someone dying in terrible pain, without any care or [help with] transition, is enormous. A palliative care approach is to prevent suffering in those who are dying and those who survive. Not just to reduce physical pain, but to give some comfort, to reduce the caregiver’s guilt, to help the family find language to talk about their grief. It’s very cheap. The knowledge that we have today can give comfort now. And it can be widely dispersed while we do the rest – while we work toward early diagnosis, treatment, and cure.”

—Kathleen M. Foley, M.D.,
IPCI Medical Director

care of patients in pain as antiretroviral drugs are for HIV or antibiotics are for infection.

Indeed, if the poor have long accepted suffering as the wages of death, research shows that such acceptance does not mean toleration. “A day lived with the certainty of experiencing severe pain is of very low value, perhaps even lower than death itself,” writes IPCI Medical Director Kathleen M. Foley.⁷ Translation: *People would rather die than live through persistent excruciating pain.* This is as true for the poor as it is for everyone else. Indeed, patients in resource-limited countries have been found to place as much value on pain relief as those in high-income countries, or even more.⁸

Global Partnerships: The Necessary Next Step

The obstacles to implementing palliative care in resource-limited countries are many. Health care systems are underfunded and inadequately managed; staffs are eroding because of deaths from AIDS; palliative medicines are unavailable, and national policies prevent them from becoming so. In addition, many countries in the developing world face political instability, natural disasters, and famine.

For palliative care services to take root and grow in the developing world, the wealthier countries must help the poorer ones, and they must coordinate their efforts.⁹ But the promise of international partnerships goes beyond money. The International Palliative Care Initiative is forging, nurturing, and sustaining partnerships, which yield mutual instruction, respect, and solidarity in bringing comfort and dignity to the ill and dying.

Looking Backward, Looking Forward: A Brief History

The Open Society Foundations International Palliative Care Initiative is now a decade old. But the hospice/palliative care movement is far older than that.

In 1843, when the Lyonnaise widow Jeanne Garnier opened the first residence offering care and comfort to the dying, she looked back at those medieval monasteries and took their name: *hospice*. The name stuck, and throughout the 19th century institutions to care for dying patients spread across Europe, the British Isles, and, at the turn of the next century, the United States.

It was a time when Western medicine was being transformed. Hospitals began to see cure as their business and death as failure; doctors sent patients home to die. By the mid-20th century, medicines were developed to keep people alive for a long time. Particularly in the U.S., rather than discharge dying patients from hospital beds, doctors attached them to machines that prolonged death more than they sustained life. The needs of the patient—not only for pain management but for psychological and spiritual support—were largely neglected. Palliative care, notes Eric Krakauer, MD, director of the Vietnam-CDC-Harvard Medical School AIDS Partnership, “developed as a corrective for resource-rich medicine gone somewhat awry.”

By the end of World War II, these developments produced an increasingly focused study of the experiences of advanced illness and death, a cogent critique, and finally a body of practice. In 1964, Dame Cicely Saunders articulated the bedrock concept

of palliative care: “total pain.” To address this combination of physical symptoms, mental distress, and emotional and social problems, she called for an integrated approach that later came to be called “holistic.” Saunders founded St. Christopher’s Hospice in South London in 1967 and combined three key principles—excellent clinical care, education, and research. The hospice, which featured cheerful rooms and a peaceful garden, became the model of the new discipline, catalyzing a robust period of development.

In the U.S., a parallel movement was evolving. Elisabeth Kubler-Ross’s *On Death and Dying* became an immediate bestseller upon publication in 1969, evidence of a bursting eagerness to draw death into the light of public discussion. Kubler-Ross advocated home care whenever possible, as well as the full participation of the ill and dying in decisions about their treatment. Palliative care first began to address the needs of cancer patients who wished to die at home. But the HIV/AIDS epidemic of the 1980s gave it additional urgency—and renewed grassroots activism—as friends and families cared for their suffering and dying loved ones. By the time antiretroviral drugs could keep HIV-positive people alive and well, palliative care was there to help manage the side-effects of the drugs’ use.

In 2008 more than 1.2 million individuals and their families received hospice care in the United States. Most was delivered at home, but also in home-like residences, nursing homes and assisted living facilities, hospitals, and prisons. Hospice is the only U.S. Medicare benefit that includes drugs, medical equipment, around-the-clock access to care, and bereavement support for loved ones.

The Project on Death in America

The Open Society Foundations played an integral role in the development of palliative care in the United States. The Foundations' commitment began close to home. Founder and Chairman George Soros lived through two very different deaths. His father underwent an operation he didn't really want and died in the hospital soon after. Soros watched from behind a glass wall. When Soros' mother's death approached, she was determined to take control and joined the Hemlock Society, which promotes the right to end one's own life. Although she did not finally take that course, the active contemplation of her own death opened the way for the family to talk about and prepare for it. Recalled Soros, it was "a very positive experience for all of us."

The Foundations initiated the Project on Death in America (PDIA) in 1994. Its purpose, in the words of Medical Director Kathleen M. Foley, a neuro-oncologist with long involvement in palliative cancer care, was to "make the issue of death and dying more transparent—to identify it, articulate it, and highlight it as an area deserving study and activity, as a medical speciality requiring more systematic research and attention, and as a focus for health funding and policy."

The next year, the Robert Wood Johnson Foundation funded the landmark publication "Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment" (SUPPORT), which added evidence and moral gravitas to PDIA's mission. It found that patients approaching death suffered unnecessary physical, emotional, and spiritual pain; that doctors didn't know or didn't listen to their needs and wishes; and that their families were often left in despair and financial ruin after the patient's

death. The study made front-page news and advanced popular support for palliative care—and helped to clarify PDIA's priorities.

From the start, PDIA's board understood that what was needed was a fundamental change in the culture of dying and death—and with it, the practices and policies of hospitals and nursing homes, where almost 70 percent of Americans lived their last days. To do this, palliative care would have to become a regular part of medical and health care education.

PDIA's strategy was to identify and support leadership and professional development among doctors, nurses, social workers, and medical researchers and educators—the people who could influence institutional cultures, policies, and practices on pain and dying. On its own and in collaboration with other donors, PDIA supported numerous fellowships and training programs and the organizations that provided them, including the Faculty Scholars Program and the Social Work Leaderships Development Program. In addition, PDIA deployed training fellowships to increase the ranks of doctors with advanced training in palliative medicine and worked to achieve recognition of palliative care as a subspecialty by the major medical accreditation bodies. PDIA also funded conferences and other information sharing; arts and humanities; community grief and bereavement projects; and model programs in schools, unions, and other institutions.

As PDIA planned to close its doors, it made final grants to organizations and associations that would continue conducting research, training health care professionals, supporting medical leadership, and improving practice and policies—all toward the ultimate goal of establishing palliative care as an integral

element of the U.S. health care system. Over nine years, the Open Society Foundations committed \$45 million to PDIA.

Going Global: The International Palliative Care Initiative

In 1999, the Foundations expanded on the experience gained through PDIA and launched the International Palliative Care Initiative as part of the Open Society Public Health Program.

The Initiative, under the direction of Foley and Mary Callaway, began its work in countries of the former Soviet Union, where national Soros foundations were in place. Since then, the Initiative has spread its purview throughout Central and Eastern Europe, as well as to Africa, Southeast Asia, the Middle East, and Latin America. As palliative care has expanded, its definition has come to encompass an expansive understanding of the relief of suffering exacerbated by social and economic forces—of the father, bedridden with cancer, watching his children quit school to go to work; the sick mother caring for her ill family and unable to rest; the HIV-positive son exiled from home, living on the city streets.

In international policy and politics, the stage was set by the World Health Organization in 1986 with the publication, *Cancer Pain Relief and Palliative Care*, which announced the imperative for integrating palliative care and pain relief into national cancer control programs. The WHO also developed a monograph, “Achieving Balance in National Opioid Control Policy: Guidelines for Assessment,” which addressed opioid drug availability as an essential aspect in providing pain relief. This document’s principles were reinforced by the International Narcotics Control Board (INCB) in 1995. In

2002 the WHO began promoting an expanded definition of palliative care. Five years later the WHO’s 58th World Health Assembly called for recommendations to fund palliative care programs in developing countries and to collaborate with the INCB to improve availability of medical opioids. The call to reform overly restrictive drug policies, in order to deliver relief to patients in pain, has been endorsed by governmental and scientific bodies worldwide, including the Council of Europe and the U.S. Institute of Medicine.

Joining the call to action is a growing cadre of champions on every continent, who are organizing themselves into an array of national, regional, and global associations and alliances including the International Association for Hospice and Palliative Care, the European Association of Palliative Care, the African Palliative Care Association, the Asia Pacific Hospice Network, and the Latin American Palliative Care Association, among others. The most recent of these is the Worldwide Palliative Care Alliance, which became a legal entity in 2009 and hopes to unite the efforts of national, regional, and international palliative care associations in advocating for palliative care. Each year since 2006, World Hospice and Palliative Care Day has focused on advocacy, public awareness, and fundraising, with activities ranging from radio campaigns to conferences to concerts.

IPCI has funded this international effort to advance palliative care, helping to map the field and draft strategies, providing technical assistance and educational training, networking leaders and advocates, and supporting new and ongoing projects with grants ranging from \$1,000 to \$250,000.

“This is a unique time and perhaps a tipping point in advocacy for palliative care globally,” wrote IPCI’s directors at the end of 2005. They highlighted the potential for vastly increased

“We have built the bridge and crossed the river. Now we are putting up the structures on the other side.”

—David Prail,
Worldwide Palliative Care Alliance

funding: the \$5 billion Global Fund to Fight AIDS, Tuberculosis and Malaria; the U.S. President’s Emergency Plan for AIDS Relief (PEPFAR), which has distributed \$15 billion since 2004, with 15 percent designated for palliative care; and many other foundations committed to palliative care, such as the Diana, Princess of Wales Memorial Fund, the Foundation for Hospices in Sub-Saharan Africa, True Colours Trust, Hope Hospice, and the Elton John AIDS Foundation.

In its first decade, the palliative care community has come a long way. “We have built the bridge and crossed the river,” says David Prail, chief executive of Help the Hospices and the founding Co-Chair of the Worldwide Palliative Care Alliance. “Now we are putting up the structures on the other side.”

The IPCI Programs

The International Palliative Care Initiative grew from the needs articulated by Open Society foundations in Central and Eastern Europe. In the beginning, the strategy focused on reforming national policies to make palliative drugs available, building regulatory and institutional infrastructure, supporting public and professional education, and making palliative care a sustainable, essential part of a public health system.

To this end, the Initiative has supported programs throughout the countries of the former Soviet Union, Africa, Southeast Asia, and the Middle East—strategically positioning its grant-giving in the step-by-step execution of the WHO’s national palliative care public health model.

To date, the Initiative has supported the following efforts:

- Mapping and monitoring of global development through the International Observatory on End of Life Care
- Developing country reports for Thailand, the Philippines, Indonesia, Kenya, Armenia, and Albania
- Monitoring drug availability through the Pain & Policy Studies Group, a WHO Collaborating Center based in the United States
- Forming palliative care centers of excellence in Hungary, Mongolia, Poland, Romania, Singapore, South Africa, Spain, and Uganda
- Providing fellowships focused on drug policy in Argentina, Armenia, Colombia, Georgia, Guatemala, Jamaica, Kenya, Moldova, Nepal, Nigeria, Panama, Serbia, and Sierra Leone, as well as fellowships on cancer in Albania, Georgia, and Serbia, and on AIDS in Vietnam
- Educating policymakers and medical staff in Croatia, Georgia, Jordan, Moldova, Mongolia, Romania, Russia, Serbia, Slovenia, Ukraine, and Vietnam
- Assessing palliative care needs in Azerbaijan, Kazakhstan, Macedonia, Moldova, Tajikistan, and Ukraine

The Initiative has catalyzed a myriad of productive synergies by bringing together advocates, practitioners, policymakers, and funders in regional and international meetings and workshops, and by partnering with other funders and international organizations.

These collaborations include the following:

- Technical assistance and support to countries receiving Global Fund and PEPFAR funding
- Support of cancer prevention, treatment, and palliative care in collaboration with the WHO and the International Atomic Energy Agency on the Programme of Action for Cancer Therapy
- Integration of palliative care into cancer care programs in Albania, Georgia, Moldova, Romania, and Russia, as well as in the Middle East and Africa
- Partnerships with many national, regional, and global funding efforts

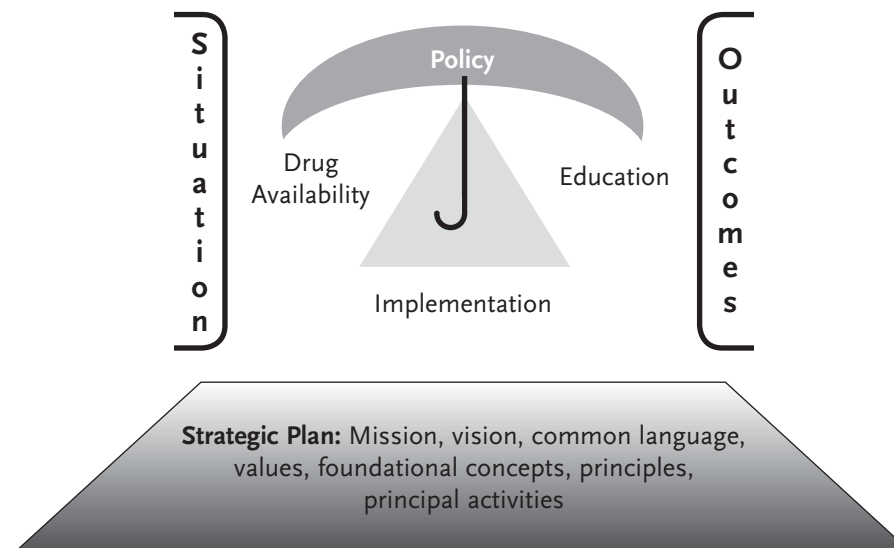


Children receiving antiretroviral medicine in South Africa

Caring for All: The WHO Public Health Strategy

Suffering in illness and death is not just a problem for individuals and their families. It is a challenge to whole populations, to be answered by villages and cities, nations, and continents. The prevention and relief of suffering is a *public health* issue. Moreover, in the last decade, the world's health care communities have come to see the severely ill and dying as “vulnerable

populations” and palliative care as one of their basic needs. Indeed, many are now calling freedom from suffering and a decent death a human right (see page 82). Public health methodologies hold the greatest promise for addressing that need and realizing that right.



Champions Make It Happen

Countless people contribute to the success of a palliative care program—from the hospice administrator who struggles to pay for blankets to the Rotary Club committee members who decide to donate part of their funds; the ad executive who creates a radio spot to the volunteer who plants a hospice flowerbed.

But palliative care does not happen without those few extraordinarily impassioned, disciplined, talented, indefatigable people: *the champions*. So intrinsic to the process are champions that the International Palliative Care Initiative and the Pain & Policy Studies Group count them as among three necessary criteria for investing in their policy reform, along with a committed government and a regulatory structure that can be changed.

The champions may come to palliative care from frustrating professional experiences, such as watching patients die in great pain. They may come to it—as so many people in the developing world do—having sat by the bedsides of their own family members and friends, as they suffered and died of AIDS or cancer. But what distinguishes the champions from the others who have witnessed the same tragedies is their extraordinary desire to do something about it, their charisma, their ability to get things done in the face of enormous challenges, and their refusal to give up.

A public health strategy aims to protect and improve the health and quality of life of an entire community. In the case of palliative care, this means integrating holistic care for the dying and people with life-limiting diseases into the health care system at every level, from the national cancer center to the mud-hut bedside. A public health approach translates new knowledge and skills into evidence-based, cost-effective interventions that will be there for everyone who needs them, when and as long as they need them.

In 1986, the World Health Organization pioneered a public health strategy to integrate palliative care into existing health care systems for cancer. Since then, the WHO has refined and enhanced its model to include HIV/AIDS and cardiovascular and neurodegenerative diseases, and focused special attention on the elderly and children.

The WHO Public Health Strategy (PHS) model for palliative care, released in 1990, is constructed on four pillars. Without any of these pillars, the edifice will not endure. The following is what needs to be done to build each pillar.

1. **Policy.** Review the national health care plan with an eye on three questions: Is relief of pain and palliative care a stated priority in the laws and regulations? Are funds and systems in place to deliver service throughout the health care system? Does the country have an essential medicines policy, and does it include opioid analgesics and other necessary medicines? Write or rewrite the national plans to provide affirmative, rational answers to all three.
2. **Drug availability.** Estimate the need for essential medicines for palliative care, including opioid drugs. Request a reasonable opioid quota from the International Narcotics Control Board. Ensure that national policy guides the

import of affordable generic opioids and establishes prescribing rules and systems for distribution, dispensing, and accountability that make pain medications available to patients when and where they need them.

3. **Education.** Train and educate health care professionals at all levels. Raise public and professional awareness about the importance of reducing suffering through pain and symptom management, reduction of psychological distress, spiritual support, and bereavement care.
4. **Implementation.** Consolidate the support of community, administrative, and clinical leaders. Have in place a sustainable infrastructure providing care in both inpatient and outpatient settings including home care; educational institutions to refresh the cadre of trained practitioners; reliable business and strategic plans; standards and guidelines; and ongoing evaluation cycled back into the system to keep improving it.

Chapters 4 through 8 of this report look at programs supported by IPCI that have exemplified progress in each of these four pillars, as well as in the supplementary, necessary functions of monitoring the progress the community is making. There are many other exemplary programs, and those highlighted here have also celebrated accomplishments in other areas.

The International Palliative Care Initiative has worked with many champions from around the world. You will find only some of their faces, voices, and accomplishments throughout this report.

Mongolia: Odontuya Davaasuren (see page 66)

South Africa: Liz Gwyther, Kath Defilippi, Joan Marston (see pages 58–59 and 81–82)

Uganda: Anne Merriman, Faith Mwangi-Powell, Henry Ddungu (see pages 27, 44–45 and 77–79)

Hungary: Katalin Muszbek (see pages 60–63)

Romania: Daniela Mosoiu (see pages 28–31)

Slovenia: Urška Lunder (see pages 55–56)

Vietnam: Nguyen Thi Phuong Cham (see pages 27 and 42)



A cancer patient receives a morphine solution in Sierra Leone, following the country's first import of the medicine.

Spotlight on Policy

A national palliative care policy makes freedom from suffering a priority—a right—for every patient, and it can stimulate the establishment of the necessary laws and regulations to undergird that concept. Pivotal to this body of law is the inclusion of opioid analgesics on the national essential medicines list, as well as the legal and practical mechanisms to make such drugs quickly and reliably available to patients either free or at affordable prices.

At the fulcrum of rational drug policy is the principle of *balance*: ensuring that pain and symptom-managing drugs can get to patients who need them, while at the same time preventing controlled substances from finding their way to illicit markets. As early as 1961, the UN Single Convention on Narcotic Drugs stressed that “the medical use of narcotic drugs continues to be indispensable for the relief of pain and suffering, and that adequate provision must be made to ensure the availability of narcotic drugs for such purposes.” This principle was articulated and adumbrated in the signal document of palliative care policy, the World Health Organization’s 2000 “Achieving Balance in National Opioids Control Policy: Guidelines for Assessment.”

In 2009, the International Narcotics Control Board reiterated and endorsed that principle in its report to the UN. The INCB is now working to develop better methods for opioid quota allotments and encouraging access as well as control.

Hammering Out Balanced Drug Policies: The Pain & Policy Studies Group

In many countries, policy is heavy on anti-drug enforcement. The hands of doctors, nurses, and pharmacists who want to relieve the pain of suffering patients are tied. Health care professionals are either unable to prescribe opioids such as morphine, or do not know how to do so. If they can prescribe opioids, low supplies may prevent them from providing patients with a sufficient dosage of the medicine.

One of the first steps, then, in instituting a palliative care program is to reform drug policy to ensure a steady, affordable supply of opioids with appropriate prescribing and distribution regulations that fit a country’s geography and political and social organization. To work toward these policies, advocates need many things. Among them: an understanding of national and international laws and conventions; a knowledge of the basics of pain management medicine; working relationships with health care leaders and policymakers; ongoing technical support; and a concrete plan to keep it all on track.

These are the tools that participants take away from two of IPCI’s central programs for advancing palliative care drug

policy: the Regional Drug Availability Workshops and the International Pain Policy Fellowships. Both are led by IPCI's close partner, the Pain & Policy Studies Group (PPSG), a WHO Collaborating Center at the University of Wisconsin. PPSG is the only policy center in the world that works specifically on opioid availability. Aside from the workshops and fellowships, PPSG provides updated data, documents, and other resources such as the annual consumption rates of morphine in countries worldwide.

Regional Drug Availability Workshops

The Regional Drug Availability Workshops pair a basic strategy with a seemingly simple tactic. The strategy is to improve access to palliative care by focusing on drug availability. The tactic is to gather all the stakeholders in one room, where they review the international policy conventions and the structures of a balanced workable drug environment, exchange experiences and ideas, and voice needs. During these workshops, stakeholders review the laws and regulations governing drug availability and recommend improvements. Before going home, they develop specific action plans for turning their proposals into policies that will support growing palliative care systems.

The first meeting, in February 2002 in Budapest, brought together representatives from Bulgaria, Croatia, Hungary, Lithuania, Poland, and Romania. David Clark, director of the International Observatory on End of Life Care, called the gathering “inspired, inspiring, and galvanizing.” Indeed, it galvanized many partnerships that are still bearing fruit.

“Innovative” is the word Faith Mwangi-Powell, of the African Palliative Care Association, used to describe the second workshop, which her organization hosted in Entebbe, Uganda, in 2006. It focused on six East and Central African countries: Ethiopia, Kenya, Malawi, Rwanda, Tanzania, and Zambia. A presentation a year later by Henry Ddungu, a Ugandan physician, APCA advocacy manager, and 2006 International Pain Policy Fellow, reported encouraging progress in several of the countries: task forces, stakeholder meetings, new rules supporting morphine availability. In two countries, little or nothing had happened. Among Ddungu's take-away lessons: small grants can make a difference. A team with a “fire in the belly” is a top requisite. And progress, while often slow, is ongoing: “You don't need to give up.”

A third Workshop, in Accra, Ghana in May 2007, brought together 68 participants from a dozen countries, who worked toward advancing drug availability in Western Africa. Each of the focus countries—Cameroon, Cote d'Ivoire, Ghana, the Gambia, Nigeria, and Sierra Leone—sent four delegates who were highly influential in their countries. Along with IPCI and PPSG, co-sponsors included the National Hospice and Palliative Care Organization (NHPCO) in the United States and Help the Hospices in the UK. WHO's Access to Controlled Medicines Division also participated in the meeting.

Three major regional opioid availability workshops were held in 2008 in Moldova, Namibia, and the Philippines. The workshop in Namibia was hosted by APCA and co-sponsored by USAID, IPCI, and the U.S.-based National Hospice and Palliative Care Organization. The workshops in the Philippines and Moldova were supported by the Open Society Foundations Public Health Program (through IPCI and the Access to Essential Medicines Initiative) and hosted by the PPSG.

These workshops cannot provide participants with blueprints, says Karen Ryan, Director of the PPSG International Program. “There is no one-size-fits-all model that would neatly fit the needs of all countries,” she and recently retired Founding Director David Joranson wrote.¹⁰ Indeed, much can be gained from the international cross-fertilization that the workshops foster. And as important as knowledge and skills are the relationships formed during intensive sessions between palliative care champions and policymakers.

International Pain Policy Fellowships

The International Pain Policy Fellowships (IPPF) is one of the strategies to improve opioid policy and systems by providing recipients with the knowledge and skills to develop and implement a project to evaluate national policy and improve the availability of opioid analgesics for palliative care in their countries. The fellows, who come to Madison, Wisconsin, for five days of intensive study and outcome-oriented planning, are already highly accomplished and motivated health professionals, including oncologists, AIDS clinicians, pharmacists, and pain and palliative care physicians. A subsequent two-year fellowship includes ongoing technical support and stipends covering 20 percent of their salaries. Kick-started by that intensive first week, the fellowship empowers them to accelerate major change at home.

The 2006 fellows, the first “class” of eight, came from Africa, Eastern Europe, Southeast Asia, and Latin America. They included four physicians and other experts from pharmacy and public health. From the experience of this first class, PPSG recognized that policy change is limited when champions do not have good contacts within government, like those solidified

in the Regional Drug Availability Workshops. Applicants for the 2008 fellowships were therefore encouraged to identify someone from the Ministry of Health to accompany them. That 2008 class included nine individuals from seven countries (Armenia, Georgia, Guatemala, Jamaica, Kenya, Moldova, and Nepal), and most were accompanied by government health officials.

Because the most important part of these sessions is what happens afterward, a group of international experts was formed to mentor the IPPF fellows.

Highlights from the 2006 and 2008 fellowships include the following successes:

- In Colombia, each district now has at least one pharmacy that stocks opioids and makes them available 24 hours a day.
- In Panama, the government expanded access to opioids by increasing the number of doctors who can prescribe the medicine, as well as increasing the duration of time a prescription for opioids is valid.
- In Serbia, the government approved a national palliative care strategy in 2009 that recognizes opioids as essential for pain relief and palliative care and provides patients with immediate release oral morphine.
- In Romania, restrictions were removed to allow doctors to use their professional judgment in prescribing opioids to patients.
- In Sierra Leone, oral morphine is now being imported into the country for the first time.
- In Vietnam, the Ministry of Health established palliative care guidelines and a national training program. There is no longer a maximum dosage for morphine, and doctors are able to prescribe medicines as needed.

2008 International Pain Policy Fellowship Team

Armenia



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Dr. Jacinta Nasimiyu Wasike, *Pharmacy and Poison Board*

Moldova



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Nepal



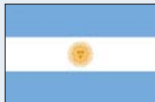
Dr. Bishnu Dutta Paudel, MBBS, MD, *Bir Hospital – Ministry of Health of Nepal*
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The 2008 International Pain Policy Fellows in Madison, Wisconsin



2006 International Pain Policy Fellowship Team

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Uganda



Dr. Henry Ddungu, MB ChB, M.Med
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Panama



Prof. Rosa Buitrago, BS, MCPH
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Vietnam



Mrs. Nguyen Thi Phuong Cham, Pharm
Ministry of Health, Department of Therapy

Romania: From Regulatory Impediments to a Beacon of Hope

The International Palliative Care Initiative began working in Romania in 2000. But advocates there had been laboring for over a decade to establish a functioning system of palliative care. The fall of the regime of President Nicolae Ceaușescu in 1989 gave the world its first glimpse of the country's "care" of the neediest: thousands of orphans, many physically and emotionally disabled, living and dying in horrific conditions. Some had AIDS, although it was hard to know how many; the Ministry of Health later revealed that First Lady Elena Ceaușescu had prohibited research or testing for the disease.¹¹

The plight of those orphans provided the catalyst for Romania's nascent hospice and palliative care movement, and in 1992, with help from the UK, a hospice for children with AIDS opened its doors in Cernavoda. Its mission: "to bring quality of life and dignity in death to children that would otherwise have neither. That same year, the UK charity Hospices of Hope helped establish a hospice for adults in Brasov named Hospice Casa Sperantei (House of Hope).

In the next decade, advocates made some progress on the legal and professional fronts. In 2000, palliative care became a medical sub-specialty. The same year, patients won the legal right to receive appropriate care also in the case of terminal illness and with it the right to palliative care, though that funding at present covers only hospitals.

The need for these laws and institutions is clear. Ninety percent of Romanians die at home. Cancer is the country's second leading cause of death, estimated in 2002 at 60,000 new cases and over 40,000 deaths each year. Two-thirds of these patients do not show symptoms until the disease is far advanced. AIDS is also a growing problem, as is a rapidly aging population. According to a UNAIDS/WHO publication, Romania may also have the highest number of HIV infections in the Eastern and Central European region—an estimated 5,500 to 14,000.

Today, more and more Romanians are receiving high-quality palliative care. The country's National Education Center for Palliative Care is a beacon of education and advocacy in the region. Hospice Casa Sperantei is an international center of excellence. And the IOELC has placed Romania in its "Approaching Integration" category, not because it has a large number of sites or accredited professionals, but because it is moving systematically toward improved—even exemplary—policy, legislation, and educational programs.

Nevertheless, along the way, Romania's progress threatened to grind to a halt. The obstacle was a drug policy that was one of the most restrictive in the world.

"What All Medicine Should Be"

Romania's palliative care movement is blessed with talented and impassioned champions. Among them is Daniela Mosoiu, MD, a practicing oncologist, specialist in palliative care education, and national development director for Hospice Casa Sperantei. She was appointed the national coordinator of palliative care education for the Ministry of Health and serves as

a board member of the Worldwide Palliative Care Association. Mosoiu has also been IPCI's principle partner in championing palliative care in Romania.

Her involvement began in 1995, in her first job as a cancer doctor. "I saw patients getting chemotherapy the week before they died," recalls Mosoiu. "That's the thing you are trained to do. You don't know anything else." While receiving painful, distressing, and futile treatment, the patients were dying in uncontrolled pain.

Looking for something better, Mosoiu joined Casa Sperantai. There, she started doing home care. "I felt for the first time that we were looking at the person behind the disease. That's what all medicine should be, especially for these patients."

Over the next half-decade, Casa Sperantai and Romania's palliative care movement grew in size, sophistication, and ambition. Between 1998 and 2002, four national conferences were held in Brasov, gathering over 400 delegates in total. By 2002, more than 1,120 Romanian health professionals had attended palliative care courses. Romania was also reaching out to its neighbors: its National Association for Palliative Care organized the First Balkan Conference in 2001, attracting 68 participants from countries including Albania, Macedonia, Moldova, Ukraine, and Yugoslavia. IPCI supported these regional efforts with grants including support to Hospice Casa Sperantai beginning in 2000 as a resource training center for palliative care in Central and Eastern Europe.

Hitting a Roadblock

Palliative care could only go so far in Romania before hitting a roadblock: drug policy. Since the early 1990s, advocates had attempted to liberalize stifling and complicated drug regulations in place since 1969. Under the old laws, doctors could prescribe opioids only for several specific conditions. Allowable dosages were low. A prescription, in triplicate, was required for authorization, and even oncologists didn't have independent prescribing authority. Medicines might have been miles and days away from a patient in pain: just one dispensing pharmacy served a district comprising, typically, 400,000 people.

Operating for decades under these laws, doctors, patients, and their families were in the dark about opioids. Most believed the drugs caused addiction; many thought morphine killed. Romania's per-capita consumption of morphine was among the lowest in Europe.¹²

Then in February 2002, Mosoiu and a few Romanian policymakers took part in a three-day regional Drug Availability Workshop in Budapest, led by the Pain & Policy Studies Group and sponsored by IPCI and the WHO. Reviewing their policies using the criteria provided in the WHO "Achieving Balance in National Opioids Control Policy: Guidelines for Assessment," Mosoiu was dismayed. "Our law was the worst," she recalls.

The conference was a turning point. Working alongside the Ministry of Health's medical director and people from its pharmaceuticals department made all the difference. "Before, we were always talking to nobody," says Mosoiu. "This was the first time the authorities said, 'OK, we need to look at this law.'" Returning from Budapest, the participating officials persuaded

Training the Trainers

Romania learned a lot from PPSG, and PPSG also learned from its four-year collaboration with Romania. “When we started, we hadn’t yet identified our three criteria” for choosing a country for technical assistance, says PPSG’s Karen Ryan. Now, the experts select potential collaborating countries on the basis of at least three pre-requisites: a strong champion; a willing government; and a regulatory regime that can be changed.

Romania learned that good policy is useless without education and subsequent changes in attitude. “We had always looked at policy change as our outcome,” says Ryan. “But you have to get closer to patient care. Romania has been a good test case, because after the policy change was made, it was clear that it would have little value without implementation. So we supported, and sent 2 faculty members from the University of Wisconsin, to help develop the curriculum to teach health care workers how to prescribe and use the drugs.”

The length of the process also helped PPSG shape its strategy. “Romania was a great part of what led us to start the International Pain Policy Fellowships, to try to increase the rate of change,” says Ryan. “It’s beneficial to work in several countries simultaneously, in case one gets delayed.” She notes that even the most conscientious champions can’t always circumvent government policy “If you have an unsympathetic Minister of Health, you could be stuck for a long time.”

the ministry to appoint a commission to review its narcotics control laws.

The combination of a dismal regulatory climate and the bright promise of human capital both outside and inside government moved the Open Society Foundations and PPSG to select Romania as a pilot country for further work. A task force was formed to move a new law and supporting regulations—and eventually a palliative care program—to fruition.

In 2003, Romania’s Palliative Care Commission presented its recommendations personally to the Minister of Health. Over the next two years, the Ministry drafted a revised law, in close collaboration with the task force. The process was led by the two officials who had attended the Budapest meeting. In 2004, a team of five Romanians, including Mosoiu, made a weeklong visit to PPSG in Wisconsin to begin drafting complementary prescribing regulations.

Romania’s Parliament passed the proposed law on November 26, 2005. In 2006, the Ministry of Health finalized and approved the regulations. Among the changes in the new rules is the authority given to all doctors to prescribe strong opioids to patients suffering severe pain from any disease. The planning during the Madison, Wisconsin workshop turned out to be the cornerstone of a solid regulatory edifice. Says Mosoiu: “We knew the regulations were going to be controversial.” Compromises were made, of course, but when the rules finally passed, “what remained was what we drafted in Wisconsin.”

Making Policy Real

Even the best policy will not change practice on its own. First, health care professionals must be aware of the legal changes; then they need the clinical skills, training, and experience to implement these changes. And finally, their prejudices and fears must be overcome.

In 2005, the Open Society Foundations supported Hospice Casa Sperantei with a 15-month grant to lead a national education project. The hospice's training coordinators developed a curriculum with a committee, including representatives of palliative care, physicians', and pharmacists' organizations, and the Ministry of Health, as well as one pediatric palliative care professor and two U.S. experts from the PPSG. Later, regulators and doctors from all of Romania's districts met to strategize setting up advertising and administering the trainings, which would be evaluated. The same year, Casa Sperantei received support from the Foundations to extend courses on service development, clinical care, and national strategies for palliative care.

To date, according to Mosoiu, the teams have trained more than 3,000 doctors and pharmacists. There is a long way to go—95 percent of the people are still not getting palliative care. Most opioid analgesics are available in Romania, apart from buprenorphine. Injectable morphine, hydromorphone, pethidine, and methadone tablets are produced in the country, and all others (including oral morphine and Fentanyl patches) are imported.¹³ Still, opioid consumption is extremely low compared with other countries. Consumption of morphine, the most-used pain medication in Romania, was just 0.0837 milligrams per capita in 2006, 45th among 48 countries in the World Health Organization European region that reported to the

International Narcotics Control Board. That is about 1 percent of the consumption of neighboring Bulgaria (6.129 mg/capita), itself fairly low on the list, at 18th of 48. Among other former Soviet countries, Slovenia and Slovakia both report morphine consumption at over 18 mg/capita, and Serbia, 0.1339.¹⁴

In spite of still-inadequate drug availability, the change in Romania has been monumental: medical pain control has been transformed from an abstraction to a reality. “Before, we were teaching pain management to doctors. But you couldn't prescribe the opioids. It was an exercise of the mind,” says Mosoiu. “Now we are doing training to implement the legislation. We are teaching the doctors, not only ‘This is how you do it,’ but ‘This is your right and your responsibility.’ People come with a different interest. They say to us, ‘I have patients in pain. What can I do for them?’”

Mosoiu and her colleagues are teaching more than how to use morphine. They are instilling the spirit that so inspired the young doctor the first time she discovered this new kind of care, care of the whole person. One story: “We had a nine-year-old boy with an advanced cancer, a nephroblastoma. His family was very poor; the parents were also illiterate and deaf. The child got chemo, but the tumor went on, and he had a lot of pain. We started treatment in the hospice, but he wanted to be at home with his parents. So we had to be very creative to talk to someone who cannot hear. You cannot write to try to help them understand.” Finally, the child learned how to administer his own medicine. In the end he was dying comfortably, sometimes being admitted in hospice, and also receiving care at home. “Suffering can be so complex,” reflects Mosoiu. “You can feel, with all your knowledge, you are so helpless. But that family was so grateful. They felt there was a huge difference from what they experienced in the normal medical system.”

In March 2008 Hospice Casa Sperantei signed a protocol with the Ministry of Health to act as teacher-advisers in developing a national palliative care program. In the future, it is hoped that the kind of care Casa Sperantei delivers will be “the national standard.”

Financing Palliative Care

How will palliative care be paid for in the developing world? How will appropriations be wisely allocated and funds effectively used? What are the right measures of cost and benefit for palliative care, and how can data analyses be used to enhance affordable care? *In other words, what are the economics of sustainable palliative care in resource-limited countries?*

With palliative care development under way in many countries, this is the question that must be answered by national ministries of finance and of health and university economists, and that looms over the bookkeeping ledger of clinics and hospices from Tanzania to Georgia to Vietnam. The question of sustainability also faces the international donor community as it seeks to leverage its assets to the fullest extent.

To face these questions now and get ready for what lies ahead, the International Palliative Care Initiative undertook a series of finance-related initiatives. In 2007, in collaboration with Kings College London and Cicely Saunders International, IPCI convened the first Health Economics of Palliative Care meeting. In addition, it has mapped the international donor universe and helps potential grantees find ways to access funds.

Costs and Benefits: The Health Economics Meeting

Palliative care is cost effective and can be provided regardless of resources. Morphine, in most forms, is cheap—“cheaper than a loaf of bread,” said Anne Merriman, MD, of Hospice Africa Uganda. And by reducing the use of hospital beds, lengths of stay, and emergency room visits, palliative care can reap savings for a health care system and the patient. Catalonia, for instance, realized an estimated savings in 2005 of about 48 million Euros for all patients in the province. Studies in Catalonia and throughout Spain estimated the average savings per cancer patient admitted to specialized palliative care units at 2,250 Euros.¹⁵

Economic arguments are often made by advocates knocking on the doors of ministers of health or finance, especially in the poorest countries, where it is hard to make a case for pain relief when the government and the economy can’t provide vast numbers of people with food, clean water, and decent shelter. Low expense is a good argument, as far as it goes. But it has an obvious flaw. “You wouldn’t want to use palliative care to deprive people of other treatment they should get,” says Irene Higginson, MD, professor of palliative care and policy at Kings College London and co-organizer of “Health Economics of Palliative Care: Research Methods and Funding Approaches,” convened in London in November 2007. Indeed, notes Higginson, if expenses were the only criterion, then doing nothing would be the best practice of all.

Where costs are concerned, there is another pertinent argument: “End-of-life health care is reputed in many studies to cost large amounts of money: in the U.S., 12 percent of Medicare

dollars, in the UK 18 percent of hospital bed-days spent in the last year of life,” says Higginson. The claim that end-of-life care is costly—the implication, too costly—was one of the prime motives for the Health Economics of Palliative Care meeting. The two-day conference brought together health economists, policymakers, advocates, and funders from four continents—Europe, Asia, Australia, and North America—to grapple with the complex issues of financing palliative care. They began with the most basic principle: that it is not enough to ask how much palliative care costs. The equation has another, crucial half: “The big issue is: what is the cost-benefit [balance] of palliative care?” says Higginson. “For economists, the question is how to put that data together. For advocates, it is how to make the case” to spend health care funds on palliative care.

Wanted: Better Data

Along with the basic questions of how to fund, and keep funding, palliative care, participants traded information about their own financing systems and discussed what models are transportable—both among developing nations and between developed to developing nations.

A major goal of the meeting was to enlighten economists about what information practitioners and advocates need, and to discuss ways of collecting, analyzing, and deploying it. Higginson says that a substantial volume of reliable studies, derived from international data, show a quantifiable benefit of palliative care in the prevention and relief of suffering, not just for patients but for their caregivers and survivors. Some studies suggest cost savings, she adds, and none that she knows of show that palliative care adds to a health care budget.

Still, she avers, good economic data on many aspects of end-of-life and palliative care are missing. There are deficiencies at every stage of research. Basic definitions are inconsistent, in part because their theoretical underpinnings are yet to be fully worked through. For instance, how is need defined, and by whom—patients, caregivers, doctors, or administrators? How do economists measure needs that are not easily put into fiscal language? What numbers can represent the need to be free of anguish, the need to have a useful life even in the midst of illness, the need for hope? In 2005, IPCI supported Higginson and her King’s College colleague Richard Harding in developing a global template for palliative care needs assessments that allow standardized evaluations and comparisons of palliative care development in countries around the world.

Problems persist in how data are collected—for instance, a failure to aggregate the various elements of cost: health services, social care, and informal costs. And evaluation vexes economists, who suffer from a shortage of outcome methodologies and measures that are appropriate to palliative care. A big help, says Higginson, would be the incorporation of health economic questions in other evaluative studies.

In spite of these shortcomings, economists can firmly substantiate one central fact: palliative care is economically smart, because it “transfers care out of acute settings into the home and away from technology to people care,” says Higginson—in other words, from more expensive settings and practices to less expensive ones. Focusing more resources on community and home-based care and less on large institutions has been widely shown to be a cost-effective health delivery approach.¹⁶

Social Priorities

Economic policy reflects social priorities. Poverty does not always predict an unwillingness to spend money on palliative care. For instance, the government of Uganda, a very poor country, provides free opioid analgesics to anyone who needs them (see page 44). Mongolia has used scarce dollars to make huge health care strides (see page 65). Even a country at war need not neglect the alleviation of the pain and suffering—or so suggests the title of an address by two Israelis at the 2007 Congress of the European Association for Palliative Care: “The Battle for Palliative Care During Wartime.”

Still, needless to say, the developing world faces huge financial hurdles in providing palliative care.

But the challenges are not exclusive to the developing world. Changes in cancer care in wealthier nations mean that patients undergo more treatments later in the course of the disease, suffering serious side-effects when their bodies and spirits are frailest. They need palliative care. In the United States, as the “baby boomer” generation ages, health care workers face older, sicker—and many more—patients. “We are going to need economical ways to do this,” says Higginson, “because there will be a lot more people dying.”

In setting its spending priorities, any rational health care policy must rest on a solid foundation of uncompromised economic data and analysis. The Health Economics Meeting helped lay the cornerstones of that foundation for palliative care. The meeting raised awareness among health economists and policymakers; catalyzed research and promotion of its funding; and incubated collaborations toward investigations in areas that need

pursuit. To disseminate the meeting’s benefits, Higginson and colleagues edited a special health economics half-issue of the *Journal of Pain and Symptom Management (JPSM)* on palliative care financing that was published in 2009.

Informing the Process: The Donor Study and the Global Fund Project

“The levels of funding necessary to cover essential palliative care services are usually far beyond the financial means of developing countries,” wrote IPCI directors Callaway and Foley, along with other authors, in the May 2007 issue of the *JPSM*. Palliative care often falls to nongovernmental and voluntary organizations, including faith-based groups, which depend on donations to pay their bills. In order to meet the needs of these providers, and deploy both human and financial resources fairly and effectively, the international donor community must work together.¹⁷

To help ensure the continued availability of funds to build palliative care capacity and keep the services going for years to come, IPCI has recently put its financial support behind two projects aimed at enhancing international donor collaboration and enabling grantee access to funds.

The Donor Study

Which organizations are giving money to hospice and palliative care in the developing world? How much are they giving (in grants of what size)? In which countries or regions do they operate, and in what kinds of activities, organizations, or populations are they interested? What are their funding criteria and terms of reference?

Such information, usefully organized, is critical both to donors wishing to leverage their giving to optimal effect and to applicants facing a bewildering array of potential grant-givers, some maintaining high profiles and others operating virtually invisibly.

That was the starting point of a 2006 meeting in Washington, cosponsored by the Open Society Foundations and the Office of International Affairs of the National Cancer Institute, called “Advancing Collaboration and Synergy for Palliative Care in Cancer and AIDS in Resource-limited Countries.” Meeting participants concluded that a rigorous guide to international donor activity was needed.

In 2006, the Foundations commissioned the International Observatory of End of Life Care to produce such a directory. In addition to identifying the donor organizations and gathering, analyzing, and organizing the pertinent data about them, the project aimed to highlight strengths and weaknesses in the grantmaking process and recommend ways to expand funding collaborations and partnerships.

After a thorough literature review, the observatory conducted an electronic survey of 354 donor organizations in five target regions. In 2008, the observatory published the review online and in print as *A Review of Donor Organizations That Support Palliative Care Development in Five World Regions*.

Although the information-gathering had its admitted limitations (most notably, the survey response rate was only 18 percent), the project yielded many intriguing and useful findings. The group was able to identify eight types of donors, the largest category of which was humanitarian organizations, comprising about half the identified organizations, followed by faith-based donors, numbering 71.

Palliative Care Donors by Type

Organization	Number
1 Multilateral	9
2 Bilateral	32
3 Humanitarian	124
4 Faith-based	71
5 Business	53
6 Hospice Support	33
7 Association (Int/Nat)	22
8 Other	10
<i>Total</i>	<i>354</i>

Because many donors were reluctant to disclose financial information, such as funding levels and criteria, the study did not compile a complete list or ranking of total or per-project giving by donor. However, the Global Fund and PEPFAR have contributed significantly to palliative care programs. As for private donors, aside from the Open Society Foundations, the Diana, Princess of Wales Memorial Fund and Eleanor Foundation gave generously for palliative care development in a fixed number of African countries, with projects receiving as much as £150,000. In Asia, the private Singapore-based Lien Foundation gave as much as U.S. \$800,000 to a single recipient, and the Li Ka Shing Foundation, based in Hong Kong, has distributed HK \$8.3 billion since its inception in 1980. Hospices of Hope, based in the United Kingdom, has made a long term commitment to palliative care development in Romania.

An analysis of donor activity in different regions may lead to the most concerted realignment of priorities in the future.

The study found substantial imbalances in the dispersion of funds. Giving is disproportionately concentrated in Central and Eastern Europe, the former Soviet Union, and Africa. By contrast, only 6 percent of donors were active in Latin America. And China, with a fifth of the world's people and a behemoth of an economy, has just five donors, or 1 percent of the total.

The authors of the donor study recommended an expansion of the project, including the following elements:

- A continually maintained global register of international hospice and palliative care donors.
- An awareness-raising campaign to focus attention on worldwide need and the disproportionate activity of donors.
- A glossary of hospice and palliative care terms for donors.
- A more detailed investigation into palliative care and its funding in China.
- In-depth interviews with key figures to explore problems and their solutions in advancing palliative care worldwide.

Global Fund Project

The Global Fund to Fight AIDS, Tuberculosis and Malaria is one immense potential fount of funding for palliative care. A partnership of governments, civil society, the private sector, and affected communities, the Fund dramatically leverages money from other donors to enable health care providers to “scale up existing programs to a level commensurate with need or initiate new programs where none existed due to a critical shortage of funds.”¹⁸ With such donors as the EU and the Bill and Melinda Gates Foundation, the Global Fund has attracted \$4.7 billion from 2001 through 2008. Its grants have ranged from \$7.5 million to \$55.9 million, with terms as

long as 11 years. It aims to ramp up its giving to \$6 billion to \$8 billion annually.

Because the requirements of applicants for such major money are complex and extensive, IPCI is supporting Help the Hospices in enhancing potential grantees' chances of success. The project offers technical assistance in grant-getting strategies and tactics to HIV/AIDS palliative care advocates in resource limited countries that hope to attract Global Fund support. Such support is extended as a sub-category of grants for HIV/AIDS prevention, treatment, and care services.

The project has two stages. The first, running from 2007 to 2008, began with research of the experiences that hospice and palliative care services have had with the Global Fund. The findings are being used on both sides of the funding equation to enlighten grantees and the Global Fund on issues and gaps in funding.

For grant-seekers, the information has been incorporated into a toolkit (available at www.helpthehospices.org.uk) and training sessions offered at palliative care and AIDS conferences. The sessions bring together successful and hopeful applicants to analyze strategies and share lessons. The mission and mechanics of the Fund and its application process are also discussed. Help the Hospices keeps its members apprised of Global Fund calls for proposals and of its own activities engaging with the Fund.

On the donors' side, Help the Hospices is seeking to educate the officers of the Fund's country coordinating mechanisms, which judge and administer its grants, as well as officers at the Fund's donor organizations. In April 2008, Help the Hospices circulated a brief to these decision makers on palliative care

and how it enhances HIV/AIDS care, including examples from the donors' own grantees.

The second stage of the project will target resource-limited countries for proposal development and advocacy to the Global Fund.

Help the Hospices chief executive David Prail, a founding member and co-chair of the Worldwide Palliative Care Alliance, thinks this is a propitious moment for these projects. Only a short time ago, he says many clinicians, policymakers, and funders didn't know what palliative care was, much less why it is necessary. "Now the discussion is not about 'what' or 'why' but 'how.' The question becomes: how to develop it under whatever constraints there may be." With some kind of palliative care programs running in 115 countries, he continues, "the big challenge is how can we keep these things going? This is why IPCI is trying to influence funding for sustainability from the major donors."



Families wait for medicines outside a pharmacy in Uganda

Spotlight on Drug Availability

Even countries with good policies often struggle to get drugs to pharmacies and clinicians and, from there, to patients. The second pillar of a palliative care public health strategy, then, is Drug Availability. Many factors outside policy and inadequate structures—for instance, economics, geography, and culture—help explain global inequities in morphine consumption. In 2003 six of the world’s countries—all in the developed West—accounted for 79 percent of consumption, while the developing world, comprising 80 percent of the global population, used only six percent.

In addition to helping individual countries create the policies and systems that enhance the flow of pain control drugs, the International Palliative Care Initiative supports regional information sharing and strategic collaboration in overcoming the obstacles to opioid analgesic availability.

Why Opioid Analgesics?

“Patients with advanced illnesses—cancer being the model—experience a lot of pain. You also have patients with breathlessness, for instance, from congestive heart failure. And morphine has been demonstrated to be the best, simple, easily available medicine to control both pain and shortness of breath. Anyone who has any experience with pain or breathlessness knows it is overwhelming, incapacitating. You can’t think, you can’t read, you can’t function. That is no way to live. People don’t need to have that level of incapacity. We have the tools; we can treat those symptoms. With opioids, we can allow people to live and have meaningful experiences, even in the face of advanced illness.”

—Frank Ferris, *San Diego Hospice & Institute for Palliative Medicine*



Vietnam: No More “Screaming Rooms”

Just a few years ago, at the Mai Hoa AIDS Center, outside Ho Chi Minh City, there was a “screaming room.” Most of the center’s patients, including children, came there to die. “When a dying patient had severe pain or distress, it upset the other patients. So [the nurses] would take him or her to the screaming room,” explains Eric Krakauer, a physician, Harvard Medical School faculty member, founder of the Vietnam-CDC-Harvard Medical School AIDS Partnership, and IPCI consultant. “The staff stayed with the patient, kept her clean and fed, held her hand and comforted her as best they could. But they had no [antiretroviral drugs] or opioids. They could provide 95 percent of what is needed—shelter, good food, compassion, respect, and solace,” Krakauer adds. “What should be the easy part, a few medications, is what they didn’t have.”

Today things are much different at Mai Hoa. All patients in need are being treated with ARVs; the children are going to school and playing in the garden. Deaths are now infrequent and those who do die have their pain relieved. There is no longer a need for a screaming room.

Thanks to substantial funds from the U.S. President’s Emergency Plan for AIDS Relief and, since 2006, the targeted support of IPCI, Vietnam is working to integrate palliative care into its health care system and to make including opioids

Dr. Eric Krakauer treats a patient in Hanoi

available for pain relief. But to go forward it has had to battle a two-headed dragon of a drug problem, whose name might be “Too Much and Not Enough.”

A Two-headed Dragon

The words “drug availability” strike a grimly ironic chord in Vietnam. On one hand, there are too many illicit opioids to be had: among its 86 million people, an estimated 150,000 are addicted to heroin. Injection drug use is the major driver of Vietnam’s AIDS epidemic. An estimated 263,000 people were infected with HIV at the end of 2005; about 14,000 of them died that year, an increase of 55 percent from just two years earlier. Of injection drug users, 60 percent are infected with HIV.¹⁹ Although ARVs are far more available than they were only a few years ago, there still are not enough for everyone in need, and people living with HIV often do not seek medical care until they are gravely ill with AIDS or related illnesses such as tuberculosis.

Cancer also appears to be growing more prevalent, with approximately 200,000 new cases and 70,000 deaths in 2006, according to the Ministry of Health.²⁰ Only five percent of cancer patients get prompt treatment; most are not diagnosed until they have far-advanced disease and are not curable.

Despite the great need for pain relief in Vietnam, the country’s traumatic historical experiences with opioids seem to have given rise to extremely tight controls on their medical use. As a result, “opioid analgesics are not readily available in Vietnam.”²¹ In 2004, the licit per-capital morphine consumption was 0.1 mg, ranking Vietnam 122nd among 155 countries reporting to the International Narcotics Control Board.

Vietnam’s antipathy to opioids is rooted at least in part in its colonial period when the French encouraged opium use as a means of social control. During the Vietnamese-American war, American and South Vietnamese soldiers supported a large black market in heroin. In the last decade, heroin has become closely associated with HIV and just as feared. These painful experiences and associations with illicit opium and heroin generated fear of all opioids, even those that are used routinely elsewhere for pain control and other medical uses—and Vietnam instituted drug policies reflecting that aversion. Until recently, the regulations were such that few doctors prescribed strong opioids and few pharmacies carried them. In some large or densely populated provinces, only one or two pharmacies sold a strong opioid.

Also, ironically, as economic liberalization in Vietnam markedly reduced the overall poverty rate over the last two decades, health care has become less accessible to many. Twenty years ago, although the country was very poor, health care was free to all. In 1989, user fees were instituted. By 2000, 63 percent of health care was privately funded, and in 2002 only 16 percent of Vietnamese had health insurance.²² Today, a growing number of people carry health insurance, and government programs cover the neediest, says Krakauer. But for millions of others, cost is often an impediment to care.

Although Vietnam’s first palliative care program was in place by 2000, it was not until 2005 that a national palliative care initiative began. That year, with PEPFAR funding, the Ministry of Health undertook a palliative care rapid situation analysis (RSA) of five representative provinces with technical assistance from Krakauer. The RSA found that severe chronic pain is common among AIDS and cancer patients; yet only five percent of clinicians reported that oral morphine was available to them,

and injectable morphine, though more available, was rarely used. It also reported a dearth of palliative care training for health care workers and of psychosocial support for people living with AIDS and their families. Asked to describe their psychological states, 79 percent of patients with HIV or AIDS said they were “unhappy” or “very unhappy”; 87 percent of cancer patients said the same.

The opinion leaders and health care workers surveyed overwhelmingly recognized the need for pain control, and most supported prescription morphine for use at home. In concurrence with the WHO public health strategy for development of national palliative care programs, a conclusion drawn from the RSA was that policies were needed that balance measures to limit diversion of opioids for illicit use with those to maximize availability of opioids for medical use. The RSA identified the need for national palliative care guidelines and training and certification in palliative care for clinicians. It called for palliative care services to be implemented at all levels of the health care system, and gave special weight to the needs of sick children and orphans.

In 2006, the Ministry of Health released its guidelines on palliative care for cancer and AIDS patients, the development of which was funded by PEPFAR. These guidelines adapted international palliative care principles and modern medical techniques for the local clinical situation.

Open Society Foundations Support

In response to the critical need in Vietnam for review and revision of the nation’s opioid policy, the International Palliative Care Initiative and the Pain and Policy Studies Group (PPSG)

selected Ministry of Health Senior Pharmacist Nguyen Thi Phuong Cham as an International Pain Policy Fellow. Cham, along with her supervisor, Luong Ngoc Khue, MD, participated in the inaugural intensive training and planning conference of the International Pain Policy Fellowship in late 2006. Technical assistance for the review of laws and regulations was provided by David Joranson of PPSG and Krakauer, who is also a member of PPSG’s International Expert Collaboration.

In early 2007, the Open Society Foundations sponsored a national workshop on opioid policy in Hanoi where all stakeholders, including the Ministry of Public Security and domestic and international drug regulators, could discuss plans for creating a balanced and responsible opioid policy.

After two years’ work, on February 1, 2008 the Ministry of Health released a radically liberalized set of opioid prescribing regulations that are much more in accord with international standards. The regulations mandate that one pharmacy in every district of the country keep strong opioids in stock for patients.

At the same time, PEPFAR and the Open Society Foundations supported Krakauer to develop basic, advanced, and fellowship curricula in palliative medicine for the Ministry of Health and to lead training courses. Krakauer, who previously directed a \$3 million project funded by the U.S. Centers for Disease Control to train Vietnam’s doctors and nurses in HIV treatment, focused initially on training and mentoring Vietnamese palliative care specialists to become future trainers themselves. “Our trainees often are unfamiliar with the new national palliative care guidelines and opioid prescribing regulations,” notes Krakauer, “and therefore are still reluctant at first to use strong opioids to relieve severe pain. But we always teach at the bedside as well as in the classroom, and there are many ‘eureka’

moments. We always ask to see the sickest patients, with the most severe pain or complex symptoms. And [with morphine], we usually are able to relieve severe pain within minutes or hours and without causing significant side effects. Our physician-trainees see this, and the ‘opiophobia’ begins to dissipate.”

In spring 2008, Krakauer worked with the Ministry of Health to pilot a fellowship and certification program in palliative medicine in Hanoi to train palliative care specialists and leaders for Vietnam. With support from the U.S. Cancer Pain Relief Committee and IPCI, he then provided the fellows and Vietnamese colleagues who joined him on the faculty with seed funds to develop palliative programs or carry out palliative care research at their home institutions. Gradually, palliative care programs are getting started around the country, both in hospitals and in the community where most end-of-life care will be provided. Most Vietnamese wish to be at home when they die.

“For traditional Vietnamese, the ancestors, those who have departed, are still very present in every day life,” explains Krakauer. Indeed, the typical Vietnamese home has an altar to the ancestors; graves are often placed in the rice paddies, so the ancestors can be in the fields with their families. But for a living person to become a contented ancestral spirit, she or he must have a good death. “There are various things that can cause the soul to become angry and lost, to wander separated from home, family, and the other ancestors,” continues Krakauer. “These include dying a painful, sudden, or violent death, and dying away from home. The best way to assure your soul joins contentedly with the ancestors is to die peacefully at home, not in a hospital. This creates a huge challenge to deliver professional, and sometimes intensive, palliative care. But I have no doubt that this can be done.”

Another major challenge, and a source of terrible suffering on a massive scale, is the stigmatization of people living with HIV, associated both with the “social evil” of drug use and with the despised history of colonization and foreign invasions. People with HIV are ashamed to go for help, and also afraid: The RSA found that 45 percent of people with HIV had experienced stigma or discrimination. As a result, people with HIV are afraid to seek medical care. Even in a culture where family ties precede birth and outlive death, and where family identity supersedes personal identity, people with HIV may be shunned by their families. Their families, in turn, may be shunned by neighbors. Widows of husbands who are believed to have had AIDS are often ostracized from the community and unable to find employment.

A comprehensive new HIV/AIDS law prohibits discrimination in housing, employment, medical care, and even social relations on the basis of HIV status. Social change does not happen with the stroke of a pen, of course, but in this highly literate and organized society, says Krakauer, it can happen quickly.

In some ways, traditional Vietnamese culture is very conducive to palliative care. Indeed, the West could learn a lot about care of the sick and dying from Vietnamese. There, to be old is to be respected; it is both a duty and an honor to care for one’s parents. A good death is a peaceful death at home, without pain and without invasive life-sustaining treatments. President Ho Chi Minh, who remains greatly revered, believed that doctors are obligated to care with kindness for all patients and especially for the most vulnerable. His famous dictum could be a motto for palliative care: “Doctors must be gentle mothers.”

Spreading Relief Across Africa

Even before he finished his medical training in 1998, Henry Ddungu knew what he wanted to do. A general practitioner, he was treating many patients with AIDS. “Access to treatment and care were almost nonexistent. We didn’t have any medicines, not even anti-fungals.” Ddungu’s patients were suffering the multiple symptoms associated with HIV—sores, diarrhea, headache—and dying in pain. The wards in which he worked were teeming. By the end of 2003, an estimated 880,000 adults and children in Uganda were living with HIV, according to UNAIDS; as many as 120,000 died from AIDS-related causes that year. Mostly due to the epidemic, Uganda has more than two million orphans.

Like millions of other sub-Saharan Africans, Ddungu had witnessed such suffering closer up: “I lost my father to cancer and many relatives to HIV, with uncontrolled symptoms.” He thought he could do better for his own patients.

In spite of the crushing burdens of poverty, disease, and political strife, Uganda has been a beacon of progressive, aggressive, and successful public health programs. Government action has helped reduce the prevalence of HIV/AIDS from 30 percent of the population in the early 1990s to an estimated six percent in 2002.

Uganda is also a pioneer in palliative care. It had provided services since 1993, including free government-financed morphine for cancer and HIV patients. In 2000, it became the first African country to classify palliative care for people with AIDS and cancer as “essential clinical care” in its National Health

Sector Strategic Plan, and palliative care is embedded in its core health care budget. Palliative care is also included in the minimum health care package in the Ministry of Health Strategic Plan. The country has worked closely with others on the continent, especially through the African Palliative Care Association (APCA), whose mission is to promote and support “affordable and culturally appropriate palliative care throughout Africa” with advocacy, policy development, education, research, monitoring and evaluation, and organizational development.

Uganda is one of only 35 countries (three in Africa) among the 234 assessed in 2006 by the International Observatory on End of Life Care that was categorized as “approaching integration” of hospice-palliative care. Among the criteria for gaining classification, beyond a reformed policy, a range of services, and education and research, a country must have “a critical mass of activists.” Indeed, Faith Mwangi-Powell, executive director of APCA, argues that concerted advocacy was the key to Uganda’s progress. The leadership of that advocacy came from Anne Merriman, MD, founder of Hospice Africa Uganda and an international leader in palliative care.

Right out of undergraduate medical school, Ddungu joined those activists. He went to work at Hospice Africa Uganda, and within a few years—besides earning a masters degree in internal medicine and completing a residency in hematology—he was certified as a specialist registrar in palliative care, the first in his country.

A Fellow for Africa

After his first two years at the hospice, Ddungu was eager to do more. He began working with the newly founded APCA in 2003. His energy and talent soon became evident within and beyond the organization. After the first APCA Regional Advocacy Workshop for East and Central Africa in 2006, IPCI Director Mary Callaway recommended that Ddungu apply for an International Pain Policy Fellowship from the Pain and Policy Studies Group. Both Uganda and Ddungu had already “graduated” from the stage of action-planning on which the sessions concentrate. But Callaway and APCA’s Mwangi-Powell—and Ddungu himself—felt that such a fellowship would empower him to accomplish far broader goals in the rest of Africa where APCA works to promote palliative care.

“I went not as a fellow for Uganda, but a fellow for Africa,” Ddungu says. The 36-year-old doctor’s mission: to propagate palliative care throughout the continent.

Ddungu says the fellowship boosted his skills and confidence in understanding technical and legal language and analyzing policy. And the follow-up technical support, from data readily available at the PPSG website to the professional advice of its experts, has been easy to get and hard to overestimate. “Whenever you have a question or a problem, you just call or e-mail and they help you.”

Ddungu now provides that same kind of support to advocates and clinicians in a fast-growing number of African countries. After the first six countries from Southern and Eastern Africa participated in pain medication access workshops, IPCI supported APCA to facilitate two more workshops for Western

and Southern Africa: a total of 18 countries brought on board in just two years. In one way or another, Ddungu has helped guide all of them.

Ddungu continues to train health care professionals in clinical practice and to do the sensitive, necessary work of overcoming their opiophobia—a problem, he learned during his fellowship, that is common in almost every country. “In Uganda in 2004, the law changed to allow specially trained nurses and clinical officers to prescribe opioids,” he says. “So in theory, we have drug availability. But even the doctors still fear using morphine. Many did their training many years ago, and they were told this is a medicine they cannot use. They would say, ‘Don’t even come to our ward with your morphine.’ But we did not give up. Now they see [the drugs] can completely change their patients’ lives.”

Ddungu is a prime example of the multiplying effect that can result when the palliative care community identifies a champion and introduces him or her to a network of experts. He is carrying palliative care knowledge and skills—and spirit—from country to country, empowering clinicians, advocates, and policymakers to do the same within their own borders. But the quiet-spoken Ddungu seems to do this by moving to the back of the room. “I try to create a forum whereby these doctors can bring up their concerns. Instead of a lecture—‘You do this and this and this’—they can air out all their fears. That is a good way of a message going into them. The question came from them, and they get an answer. That is how they can go within their own countries to carry out advocacy for palliative care.”

International Association for Hospice and Palliative Care List of Essential Medicines for Palliative Care®

Medication	Formulation	IAHPC Indication for PC	WHO Essential Medicines Model List Section, subsection and Indication
Amitriptyline*	50–150 mg tablets	Depression Neuropathic pain	24.2.1 – Depressive disorders
Bisacodyl	10 mg tablets 10 mg rectal suppositories	Constipation	Not included
Carbamazepine**	100–200 mg tablet	Neuropathic pain	5 – Anticonvulsants/antiepileptics 24.2.2 – Bipolar disorders
Citalopram (or any other equivalent generic SSRI except paroxetine and fluvoxamine)	20 mg tablets 10 mg/5ml oral solution 20–40 mg injectable	Depression	Not included
Codeine	30 mg tablets	Diarrhea Pain – mild to moderate	2.2 – Opioid analgesics 17.5.3 – Antidiarrheal
Dexamethasone	0.5–4 mg tablets 4 mg/ml injectable	Anorexia Nausea Neuropathic pain Vomiting	3 – Antiallergics and anaphylaxis 8.3 – Hormones and antihormones
Diazepam	2.5–10 mg tablets 5 mg/ml injectable 10 mg rectal suppository	Anxiety	1.3 – Preoperative sedation short term procedures 5 – Anticonvulsants/antiepileptics 24.3 – Generalized anxiety, sleep disorders
Diclofenac	25–50 mg tablets 50 and 75 mg/3ml injectable	Pain – mild to moderate	Not included
Diphenhydramine	25 mg tablets 50 mg/ml injectable	Nausea Vomiting	Not included
Fentanyl (transdermal patch)	25 micrograms/hr 50 micrograms/hr	Pain – moderate to severe	Not included
Gabapentin	tablets 300 mg or 400 mg	Neuropathic pain	Not included

Medication	Formulation	IAHPC Indication for PC	WHO Essential Medicines Model List Section, subsection and Indication
Haloperidol	0.5–5 mg tablets 0.5–5 mg drops 0.5–5 mg/ml injectable	Delirium Nausea Vomiting Terminal restlessness	24.1 – Psychotic disorders
Hyoscine butylbromide	20 mg/1ml oral solution 10 mg tablets 10 mg/ml injectable	Nausea Terminal respiratory congestion Visceral pain Vomiting	Not included
Ibuprofen	200 mg tablets 400 mg tablets	Pain – mild to moderate	2.1 – Non opioids and NSAIDs
Levomepromazine	5–50 mg tablets 25 mg/ml injectable	Delirium Terminal restlessness	Not included
Loperamide	2 mg tablets	Diarrhea	Not included
Lorazepam***	0.5–2 mg tablets 2 mg/ml liquid/drops 2–4 mg/ml injectable	Anxiety Insomnia	Not included
Megestrol Acetate	160 mg tablets 40 mg/ml solution	Anorexia	Not included
Methadone (immediate release)	5mg tablets 1 mg/ml oral solution	Pain – moderate to severe	24.5 – Substance dependence
Metoclopramide	10 mg tablets 5 mg/ml injectable	Nausea Vomiting	17.2 – Antiemetics
Midazolam	1–5 mg/ml injectable	Anxiety Terminal restlessness	Not included
Mineral oil enema			Not included
Mirtazapine (or any other generic dual action NassA or SNRI)	15–30 mg tablets 7.5–15 mg injectable	Depression	Not included

Medication	Formulation	IAHPC Indication for PC	WHO Essential Medicines Model List Section, subsection and Indication
Morphine	Immediate release: 10-60 mg tablets Immediate release: 10mg/5ml oral solution Immediate release: 10 mg/ml injectable Sustained release: 10 mg tablets Sustained release: 30 mg tablets	Dyspnea Pain – moderate to severe	2.2 – Opioid analgesics
Octreotide	100 mcg/ml injectable	Diarrhea Vomiting	Not included
Oral rehydration salts		Diarrhea	17.5.1 – Oral rehydration
Oxycodone	5 mg tablet	Pain – moderate to severe	Not included
Paracetamol (Acetaminophen)	100–500 mg tablets 500 mg rectal suppositories	Pain – mild to moderate	2.1 – Non opioids and NSAIDs
Prednisolone (as an alt to Dexamethasone)	5 mg tablet	Anorexia	3 – Antiallergics and anaphylaxis 8.3 – Hormones and antihormones 21.2 – Anti inflammatory agents
Senna	8.6 mg tablets	Constipation	17.4 – Laxatives
Tramadol	50 mg immediate release tablets/capsules 100 mg/ml oral solution 50 mg/ml injectable	Pain – mild to moderate	Not included
Trazodone	25–75 mg tablets 50 mg injectable	Insomnia	Not included
Zolpidem (still patented)	5–10 mg tablets	Insomnia	Not included

Complementary: *Require special training and/or delivery method*

* Side-effects limit dose

** Alternatives to amitriptyline and tricyclic antidepressants (should have at least one drug other than dexamethasone)

*** For short term use in insomnia

Notes:

- Non Benzodiazepines should be used in the elderly
- Non Steroidal Anti Inflammatory Medicines (NSAIDs) should be used for brief periods of time
- **NO GOVERNMENT SHOULD APPROVE MODIFIED RELEASE MORPHINE, FENTANYL OR OXYCODONE WITHOUT ALSO GUARANTEEING WIDELY AVAILABLE NORMAL RELEASE ORAL MORPHINE.**
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An Essential Palliative Care Medicines List

What medicines are absolutely necessary—and effective and safe—in providing optimal pain relief and symptom management in palliative care?

That was the question posed to the International Association for Hospice and Palliative Care (IAHPC), an organization of health care professionals, by the World Health Organization. The WHO updates its own Model List of Essential Medicines every two years. IAHPC took on the task of developing another list, this time of essential drugs for palliative care.

In 2005, the IAHPC convened a working committee, which drew up a plan of action and a set of ethical principles: the medicines had to be truly essential; applicable in any country; and the selections could not be influenced by personal or commercial interests. The group compiled a list of 21 symptoms prevalent in palliative care patients, focusing on advanced cancer and AIDS. It asked palliative care leaders from both developed and developing countries to recommend medications. Several rounds of refinement followed, culminating in consensus among representatives of 26 regional, international, and scientific organizations working in palliative care at a meeting in Salzburg in 2006. The final Essential Medicines List for Palliative Care includes 33 medicines; 14 were already on the WHO Model List of Essential Medicines.

“This list has a great deal of credibility,” said WPCA’s David Prail, who participated in the meetings to develop the list. But, he cautions, there are steep hills to climb before all of the palliative care drugs make it onto the WHO Model List. Each drug has to be individually reviewed and approved by a WHO Technical Committee. In the meantime, says the IAHPC’s

Executive Director Liliana DeLima, who led the working committee, the list is “a valuable advocacy tool to promote palliative care and opioid analgesics.”

Asia’s First Drug Availability Workshop

“You could see, hear, and smell pain,” said Henry Lu, MD, the distinguished pain management specialist who heads the Makati Cancer Pain Control Clinic in Manila. Lu was describing the atmosphere inside the tiny, dark home of a cancer patient named Lita, who lives in a poor Manila district called Tondo.

“The purpose of this workshop is really for people like Lita,” Lu continued, “to assure them that the necessary medicines for pain and palliative care are available and accessible.”

Lu was welcoming participants from Thailand, Indonesia, and the Philippines to the first IPCI drug availability workshop in Asia, entitled “Workshop on Assuring Availability and Accessibility of Opioids Analgesics for Pain and Palliative.” The three-day meeting was held in April 2008 on the white-sand resort island of Boracay Island, Aklan in the Philippines. It was sponsored by PPSG, funded by the Open Society Foundations, and hosted by the Pain Society of the Philippines. Philippine health care experts, officials from the World Health Organization’s Western Pacific Regional Office and the Department of Medicines Policy and Standards, and policy experts from the International Palliative Care Initiative and PPSG served as faculty for the program.

Like other such workshops throughout the world, the Philippines meeting brought together health care practitioners and government drug regulatory officials from the participating countries to learn about untreated pain, the causes of under-treatment, the role of regulatory and system barriers that interfere in opioid availability and patient access to pain relief, and methods to address these barriers. Speaking on the first day, Karen Ryan, director of the PPSG International Program, stressed that an adequate response to “the human imperative to treat pain will depend on the successful collaboration between the health care and drug regulatory bodies.”

Participants from the three countries networked, exchanged information, and discussed common problems. Then, also as in earlier meetings, they split into country groups to assess their specific situations and prepare action plans for progress. In Indonesia, for instance, where HIV is still a relatively small problem, cancer is the sixth greatest cause of death, with 200,000 to 350,000 new cases presenting annually. For 89 percent of these patients, pain is the chief complaint. Yet “pain management for cancer and HIV are low priorities,” their plan said, and doctors are uninformed about it, in a health care system overwhelmed with treating avian flu, malnutrition, and tuberculosis.

In Thailand, cancer is the leading cause of death and 45,000 people die because of AIDS each year. Yet physicians are fearful and averse to using opioids. Like their Indonesian counterparts, the Thai group proposed education as a crucial element to bettering pain management. In addition, Thailand’s health care system struggles with wide gaps between rich and poor, which also affect the availability and accessibility of pain medications. Among 64.8 million people, 25 million lack health

insurance, and pain medicines are available almost exclusively in Bangkok and in private hospitals.

Philippines Health Secretary Francisco Duque III, giving the workshop’s keynote address, named physicians’ and patients’ fears, burdensome licensing regulations, and insufficient supply as contributors to his nation’s lagging opioid consumption—low in comparison both to the need and to the usage in neighboring countries. He vowed a systemic response to this insufficiency and made his promise concrete: “To narrow the gap of accessibility and availability of drugs, especially for people living in remote areas.” The Secretary announced the availability of 10 million Philippine pesos for the purchase of opioids (such as morphine) to alleviate the pain of poor patients suffering from cancer throughout the country.

Spotlight on Education

Palliative care advocates often find that they labor to reform their nations' drug policies and get the supporting regulations in place—and then not much happens.

Doctors and nurses may not know the law has changed. They may fear using morphine, having been taught that it is a dangerous, illegal drug carrying heavy penalties for misuse. Even the best informed and enthusiastic health care providers may be ignorant of the techniques of pain assessment and management and unschooled in the philosophy and practices, both medical and psychosocial, that make up palliative care.

Patients and their families may be equally phobic about opioids. Throughout the world, the drugs carry myths of fatality and the stigma of addiction or immoral living. The word “hospice” may imply the end of hope for themselves or their loved ones.

Education, both public and professional, is a crucial component of integrating palliative care into a health care system. Training methods must also be continually evaluated and, using the evidence gleaned, refined, and updated.

Professional Training: Salzburg Seminars and Centers of Excellence

The Salzburg Seminars

A central element in IPCI's global education strategy, the Salzburg Seminars in Palliative Care are five-day classroom courses held annually at Schloss Arenberg, a world-class educational facility just outside Salzburg, Austria. Along with the Austrian American Foundation, IPCI conducts regular seminars for medical professionals on topics related to palliative care; previous seminars have focused on palliative care in HIV/AIDS treatment, geriatrics, and pediatrics. Participants are predominately from Central and Eastern Europe and the former Soviet Union, although a growing number of participants from Africa and Asia are selected as well.

“Teach Us About You”

“When teaching palliative care to nurses I go around the room and ask each nurse to describe what it is like in their country when someone dies. How do they clean the body, who is present, are there rituals that are important, based in religion or long-held customs? Every time I do this I find it to be a very powerful reminder of the importance of culture. This field of palliative care is emerging as a medical specialty, and we are moving to standardize and professionalize it. At the same time, we need to remember that to advance this field or provide quality care does not mean everyone has to do everything in exactly the same way. In fact, it’s the opposite. If we are going to provide culturally relevant care, we have to be very attuned to the practices and beliefs of the culture. We can’t just go into Kenya or Russia and say, ‘Here’s the way you do palliative care.’ We have to say, ‘Teach us about you and your people and your beliefs; about how you communicate, how decisions are made. Let us work together to bridge what we know with what you know about your society.’”

—Betty Ferrell

*End of Life Nursing Education Consortium;
Salzburg Seminar Course Director*

Centers of Excellence

OSI has supported regional resource training centers that serve as Centers of Excellence in Hungary, Mongolia, Poland, Romania, Croatia, Slovenia, Singapore, South Africa, and Uganda. Some of these centers focus on education and training while others model high-quality medical services, policy advocacy, and integration of palliative care into a regional or national health care system. They also may provide policy and advocacy consultation and bedside training in their facilities to other practitioners in the region.

Among Europe’s Centers of Excellence is The International Palliative Care Initiative. The institute’s director is Xavier Gomez-Batiste, who worked as an IPCI consultant while helping to build the institute and integrate palliative care within Catalonia’s health care system. Starting as a WHO demonstration project in 1990, a collaboration between the Catalan Department of Health and the WHO Cancer Unit in Geneva, Catalonia’s palliative care system has become a model for the region.

Today, 95 percent of Catalonia is served with palliative care, which is integrated at every level of the region’s health care system from acute care hospitals to home care. Almost eight of 10 cancer patients and four of 10 patients with other diagnoses receive palliative care. Opioid consumption increased from 3.5 mg per capita in 1989 to 21 mg per capita in 2004.

These services have yielded extraordinary levels of patient satisfaction—in one study, a mean score of 8.3 out of 10. Emotional support, communication, and feelings of safety won the highest scores.²³ Aside from these human benefits to patients and their families, palliative care has proven to be a benefit to the finances of Catalonia’s health care, which is free to all citizens.

The Institute of Oncology has trained more than 5,000 health care workers in palliative care and extended its expertise in policy development and implementation to other European countries, including Hungary and Slovenia. Institute staff, especially Gomez-Batiste, speak widely on all aspects of palliative care policy, financing, education, and clinical practice.

The designation in 2008 as a WHO Collaborating Center for Public Health Palliative Care Programs will increase the institute’s reach and influence as a leader and educator throughout the world. Among other functions, it is charged with continuing its policy and educational collaborations, conducting research on palliative care effectiveness and transferability of models, and developing guidelines, benchmarks, and tools for evaluation. “Catalonia has the best integration of palliative care in the world,” says IPCI Medical Director Kathleen Foley. Its new designation will help it spread that excellence.

The Bedside is the Best Classroom

“Medicine is really a technical profession,” says Frank Ferris, MD, a radiation oncologist and director of international programs at the Institute for Palliative Medicine at the San Diego Hospice and a technical consultant to International Palliative Care Initiative. Ferris, who has conducted physician training at four Salzburg Seminars, is the architect of the evolving model of optimum palliative care professional training. Its central tenet is: *there is no substitute for bedside training*. “Yes, there are a series of facts you learn, and attitudes can be changed in the classroom,” he continues. “But if we really want to change the experience of patients and families—and that is our goal in health care—then we need to train people not only in the facts, but also need to practice the skills and integrate them into time-efficient encounters with the patient.

“In palliative care education, the goal is to get doctors to prescribe and nurses to administer opioids for pain,” Ferris continues. “In the classroom you can talk about pain assessment, causes of pain, how to do treatment, and the rest. Then you have to go to the bedside.” Also part of palliative care is sharing information and negotiating the goals of care. Palliative care professionals “need to learn how to break bad news, discuss interventions, and explore the patient’s and the family’s values with them. This is skill-building, too, and it needs practice.”

To compare the effectiveness of two kinds of palliative care training, Ferris conducted a pilot study evaluating the knowledge and competence of health care worker participants in one-week interactive didactic courses at the Open Society Foundations Salzburg Seminars with

those who took three-week courses combining a week of classroom education with two weeks of bedside training in Amman, Jordan. Ferris used standardized, validated tools and assessed the trainees on the first and last days of the program. All the students concluded the courses at a relatively high level of competence.

Ferris argues that a structured approach to education and evaluation is necessary. The pilot data, furthermore, suggest that a three-week course combining didactic classroom and bedside teaching produces more gains in both knowledge and competency; and that repetition

of the training is essential.²⁴ Ferris is conducting further research to determine the most effective configurations of palliative care training. Adapting these programs to resource-limited countries, he adds, is challenging, especially given the need for ongoing retraining and evaluation.

Although formal evaluations of bedside training are ongoing, anecdote speaks for its superior value. For instance, Ferris tells this story from the 2004 Amman course: “This one doctor was very enthusiastic about morphine, and quite proficient [in the classroom]. Then we took him to the bedside.” The time came for him to prescribe morphine for a patient, a woman with advanced cancer, in unbearable pain. “He stood there unable to move. He threw the pen back at us. Finally, we wrote the prescription. He signed it—he had to. But his hands were trembling the whole time.” Within days, the patient was walking around and asking to go home. “That was thrilling,” says Ferris. “Suddenly all the doctors wanted the drugs.” And the doctor who could not write the word *morphine* became one of Jordan’s most engaged champions of pain control and palliative care. “He personally prescribes at least a kilogram of morphine a year,” says Ferris. “But it took real bedside training for him to feel comfortable doing that.”



Dr. Frank Ferris at a patient's bedside

Training in Kiev

As part of a stepped-up effort to broaden bedside training globally, IPCI supported a three-week palliative care clinical course in Kiev, Ukraine, in November 2008. Other collaborators for the course were the International Renaissance Foundation, San Diego Hospice and Institute for Palliative Medicine, the All-Ukrainian Council on Patient Rights and Safety, and the National Medical Academy of Post-Graduate Education. The course trained 32 physician/nurse teams from 15 Ukrainian institutions all over the country including AIDS, cancer, geriatric, and hospice and palliative care centers. Forty more health care professionals took part in a three-day workshop at the beginning of the course that introduced and sensitized them to the basic concepts of palliative care. Other events brought together Ukrainian leaders and stakeholders, including the Ministry of Health—underscoring the need for supportive national drug policy and high-level engagement in integrating palliative care throughout a national health care system. Ferris was joined in leading the course by Ukrainian Course Director Anatoliy Tsarenko, MD, and Course Coordinator Olena Yakimenko.

A Slovenian Fellow Helps Change Cancer Care

Among the international fellows arriving in late 2008 at the San Diego Hospice and Institute for Palliative Medicine was Slovenia's Urška Lunder, MD. Lunder was beginning her fifth session with the program, which focuses not just on clinical training—with the emphasis on bedside training—but also on advocacy, policy development, and teaching.

Like the other fellows, Lunder is no beginner. Indeed, she has been a palliative care professional for a decade and a half and a national and regional leader for much of that time. Around 1994, the hematologist specializing in bone marrow transplants was plagued by dissatisfaction with the care she was giving her patients. Bone marrow transplantation medicine in Slovenia was highly standardized; the course of treatment was decided “not by the individual patient, but the diagnosis,” she said. “I was very unhappy being so aggressive. Half of our patients eventually died, and we didn't have much to offer in those weeks when we knew they were dying.” Around that time, her father also passed away. She became keenly interested in learning about hospice, which she began to do, in Switzerland.

Lunder soon stopped doing bone marrow transplants, and she has not looked back. With IPCI support, she founded Slovenia's Palliative Care Development Institute, based in Ljubljana, and has continued to develop palliative care throughout the nation and the region.

While practicing at the University Clinic Golnik, Lunder also speaks and teaches widely. She helped bring together the February 2008 European Union Conference: “The Burden of Cancer: How Can it be Reduced?,” hosted in Brdo by Slovenia's Ministry of Health. In that talk, Lunder discussed new documentation tools and procedures through which palliative care can be quickly adopted by countries just

coming up to speed not just in palliative care but in establishing primary care and national health systems. New policies and physician education have quickly increased Slovenia's morphine consumption; it is now above average in Europe.

How can palliative care “reduce the burden” of cancer? The answers go beyond pain management and beyond the economic advantages of shifting funds from expensive acute treatment to less costly, less aggressive care. In fact, Lunder sees palliative care as a natural constituent for cancer care, which brings new and necessary dimensions.

“In oncology,” she says, “doctors are concentrated on treatment. They usually assume that everyone has the same goal: to cure. So they discuss among the doctors and suggest to the patient what is best to do. Palliative care has the totally opposite approach. First we talk to the patient and the family to find out what is disturbing in whatever we are doing, and what the patient's and the relatives' needs and goals are.”

Lunder sees the interdisciplinarity of palliative care as crucial to improving cancer care—not least because cancer and its treatment often involve other bodily systems, symptoms, and illnesses. She lauds the collegial, egalitarian style that palliative care brings to institutional staffs, wherein doctors, nurses, social workers, and other professionals and caregivers meet together with the patient and her family to arrive at a care plan and address problems.

Lunder believes that palliative care can have a profound effect on all medicine: “Palliative care ultimately talks about life and getting old and getting sick and dying. It brings new approaches and solutions to the patient who is being treated for an advanced incurable disease, but also to the society.” Palliative care's message is about far more than medicine, she says: “This is the big picture. It is a silent revolution of stating our values and meaning, of our behavior and cooperation far before death and dying.”

Mentoring: South African Professionals “Pass It Forward”

At its 25th anniversary, South Africa's palliative care system stands as both a model of what is possible and a hard reminder of what still needs to be done. Once again, the country has innovated an effective model: the mentorship program multiplies the effectiveness and speed of professional training.

Palliative care in South Africa was catalyzed by a visit by Britain's Dame Cicely Saunders in 1979. By 1983, South Coast Hospice, one of the early hospice facilities that was started by Kath Defilippi, was welcoming patients, and by 1986 the country boasted 14 hospices across its nine provinces. Two years later, the 14 hospices joined together to form the Hospice Palliative Care Association (HPCA). The work of HPCA's members was based on the UK model: the diagnosis was cancer, and the focus was end-of-life care.

HPCA would soon have to take stock of its fledgling system and change—fast. The reason can be summed up in one word: AIDS. Throughout the 1980s, while South Africa was pouring itself into the struggle against apartheid, HIV was racing over the landscape. By the time the new democratic government took its seat in 1994, the pandemic was too widespread; it dwarfed cancer as the hospices' first priority.

Today, antiretroviral (ARV) therapy is starting to keep many more people with AIDS alive and healthier. But ARVs have not significantly changed the fact that patients don't see a doctor until they are in advanced stages of the disease. In 2005, among a population of 45 million, about 890 people died each

day of HIV/AIDS. The ravages of illness are compounded by stigma, poverty, and the emotional and physical burden of caring for infected and affected children. The need for palliative care vastly overwhelms the country's 76 palliative care facilities in its 174 health care districts.²⁵

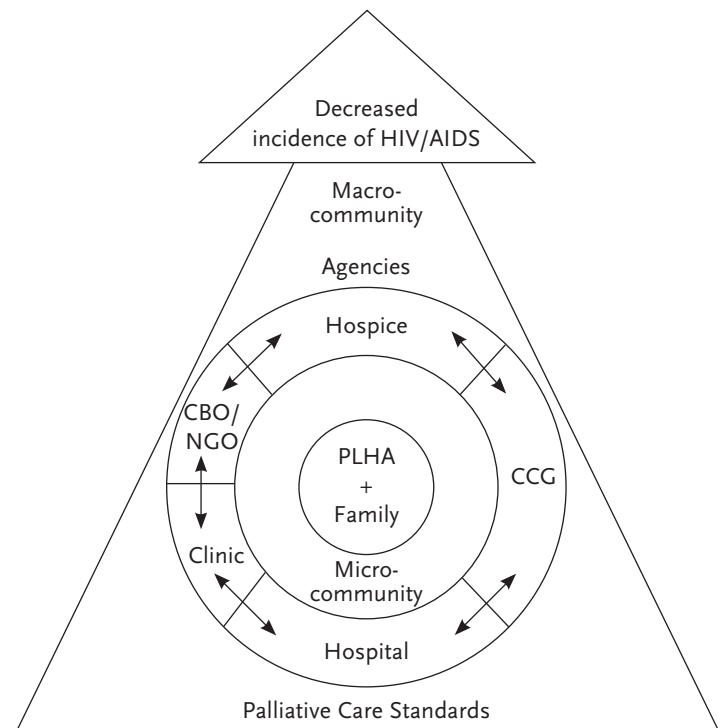
"HIV turned us all on our heads," says Kath Defilippi, HPCA's National Patient Care Coordinator one of the country's earliest palliative care advocates. "We have had to adapt to provide a more comprehensive approach of palliative care—and we have to reach far greater numbers of people."

A Community Model

What first evolved as a response to the HIV/AIDS crisis was the model that is now South Africa's core palliative care delivery vehicle: Integrated Community-Based Home Care model (ICHC). ICHC creates around the patient a web of linked services and includes prevention, treatment, care, and ARV therapies. Knowledge and resources are shared from as far away as a government district hospital to as nearby as the palliative care station in a shed in the village.

HPCA started to scale up its provision by using the ICHC model that had been developed by South Coast Hospice. But the very reach palliative care was achieving also threatened to undermine it. Without proper supervision, HPCA could spin off into well-meaning, but substandard practices. This would not do for HPCA, one of whose primary functions is to uphold the highest standards through evaluation, training, and accreditation. "Our constant challenge," says Defilippi, "is to balance coverage with quality."

To tackle that challenge, in 2002 IPCI awarded HPCA a grant to develop a mentorship program, whose expansion continues. Under the program, established hospices and community programs assess the palliative care needs of newer facilities, then help those institutions to plan and implement care. Once the



- ↔ Sharing information
- CCG Community Caregiver
- CBO Community Based Organizations
- NGO Non-Governmental Organizations
- PLHA Person Living with HIV/AIDS

new hospices are up to speed, they in turn mentor others. They “pass it forward,” as one program publication put it, “creating a ripple effect for quality palliative care.”

The mentorship program developed in two phases. In 2001-2002, the hospices with well-established programs were designated as “mentor hospices.” These hospices assessed local situations and crafted plans to involve all the key players both in the hospices and the communities. The mentor hospices also ran numerous regional palliative care workshops.

Expanding on the successful first phase, HPCA began to add branches to the mentorship tree and strengthen its roots. Full-time coordinators were funded in eight of the nine provinces to help selected “development sites” meet the criteria for HPCA funding; by 2007, 57 of these had been identified. “What we are really trying to do is to establish every one of our 76 member hospices as a palliative care resource center that can give mentorship to a host of faith-based organizations, NGOs, and others,” says Defilippi.

Cascading Quality

Along with the Council for Health Service Accreditation of South Africa, HPCA is laboring to better the quality of care. This quality care initiative is also funded by the Open Society Foundations. “What we’re doing is using these comprehensive standards to try to cascade the quality in the same fashion as the mentorship cascades the skills. The hospices get full accreditation from this external accreditation body, then use their expertise to fast-track others to reach that level,” Defilippi explains.

Liz Gwyther, CEO of HPCA and its former training chief, says that an average of 10,000 professionals and laypeople are trained annually across South Africa in anything from a basic three-to-five day course to the six-month nursing certificate. The waiting lists for the courses are overflowing.

The mentoring process is poised to expand even further. In 2007, South Africa’s Department of Health asked HPCA to give it a budget for expansion. The alliance was also negotiating with the department’s NGO Directorate for funds to do baseline assessments at an additional 234 nongovernmental home-based care sites. If palliative care were integrated into all these sites, its reach would triple, from 132 hospices and development sites to 366, serving 150,000 patients, according to Gwyther. The problem now, she says, is how to train enough staff fast enough to do all those surveys and integrate palliative care into all those new home-based programs. A tough, but enviable, problem.

Writing in the *Journal of Pain and Symptom Management*, Defilippi and her colleague Sue Cameron sum up the lessons learned in the South African mentorship program so far: “Mentorship works!” Clearly, others are persuaded that they are right. The African Palliative Care Association is piloting a program for all its member countries based on the South African model.

Ubuntu: Another Name for Community-Based Care

In spite of its modern name, Integrated Community-Based Health Care draws on an ancient African belief: Ubuntu, the idea that “a person is a person through people.” The tradition of Ubuntu makes it natural for skills to be passed between the formal and informal health care systems, among doctors and nurses, grannies, and traditional healers—all sharing a single concern: the wellbeing of the patient.

Establishing palliative care in a community “is not a matter of going in and saying, ‘Here I am with all my knowledge and all my training,’” says Joan Marston, a nurse and HPCA pediatric portfolio manager who heads the pediatric palliative care element of the mentorship program. Nor can mentors work only with the professional health care workers. “You need to work through the respected community leaders. They know who is sick or whether a child has been neglected or abandoned, and will point you in their direction.” The more rural the place, the less likely it is anyone speaks English, Marston adds, “so you must have a trusted person in the community.”

Since 70 percent of South Africans consult a traditional healer at some point, the palliative care professionals must also work with them. This can be a sensitive endeavor. On one hand, the healers “approach the body, mind, and spirit together,” as palliative care workers do. Many of the healers carry a deep knowledge of herbal medicines that can relieve nausea, diarrhea, and other symptoms, from which Western practitioners can learn a great deal. On the other hand, Marston notes, some “healers” may employ futile, painful, or harmful practices. So it is “very important that the traditional healers understand modern palliation.”

If real trust is achieved, the whole community works together—ICHC at its best. “The patient goes to the healer, but she is still having pain,” says Marston. “The traditional healer will call a nurse, who will pay an urgent visit to bring those professional skills.”

South African nurses are about to win the authority to prescribe and administer opioid analgesics, which will cut the sometimes days-long wait for the drugs to arrive from a distance.

“Then it is the community worker who does the home visits and lay counseling, who sees that children have immunizations and that the patient is washed and kept clean.” The community worker is often an elderly “wise woman,” adept at everything from herbal medicine to midwifery. What she does “is an extension of a nurse’s role.”

But “the most important group,” stresses Marston, “is the family—the granny, older sibling, or parent, who might be sick, as well.”

Popular Education: Hungary’s Media Campaign Gives Meaning to “Hospice”

In 2000, the city of Budapest gave a gift to the Hungarian Hospice Foundation that excited its officers: an old kindergarten building to convert to the first hospice in the nation. But the building, needing extensive renovation, also overwhelmed them. The fact was, Hungary’s decade-old hospice movement “was dying,” recalls Katalin Muszbek. “We were getting weaker and weaker and very fatigued and even a little bit hopeless.” Muszbek is a psychiatrist who worked with terminal cancer patients, a founder of the Hungarian hospice movement and the foundation, and now director of Budapest Hospice House—that former kindergarten. She is also a longtime IPCI collaborator and consultant and a champion both for Hungary and the Central and Eastern European region.

Unlike other countries, Hungary did not have a restrictive opioid policy. Morphine was the recognized medicine for pain—at least on paper. But the vast majority of doctors, even those treating terminal cancer patients, were not using it. As for comprehensive palliative care, a few hospice services, mostly home-based, were scattered around the country.

By the end of the 1990s, palliative care development “absolutely stopped,” says Muszbek. The reason: “We didn’t have the regulation and we didn’t have the finances.” But they didn’t have something else that is crucially important: popular and professional recognition and knowledge of palliative care. The advocates suspected they would get neither laws nor money until Hungarians understood and embraced the concept.

A poll taken in 1999 confirmed their hypothesis. In a public survey, 100 percent of respondents said they didn’t know the meaning of the word *hospice*.

Muszbek enlisted the help of a well-known Hungarian actress who had contacted the Foundation wishing to volunteer after her grandmother died peacefully in hospice. Another sympathetic ally was the head of the Budapest office of McCann Erickson, the global advertising firm. He had also experienced a family death that moved him to want better care at the end of life. He offered a national media campaign, gratis. It would be the largest ever for health care in Hungary’s history.

Testimony

The campaign identified three goals: to promote integration of hospice/palliative care into the national health service; to raise awareness of hospice/palliative care and educate people that they can die peacefully and with dignity; and to draw policymakers’ attention to the plight of suffering and dying patients to mobilize them to institute laws and regulations to make palliative care successful.

Three TV spots ran on five Hungarian-speaking channels for two two-month stretches, six months apart. All were entitled “Testimony” and featured the Hungarian actress, another movie and television celebrity, and a male dancer and choreographer from the world-famous Belgian Béjart Ballet. An award-winning producer and cameraman were brought into the team. Then, working alongside the advertising firm and filmmakers, the palliative care advocates struggled to find the right tone and text. “Death and dying are taboo,” Muszbek explains. “We did



Katalin Muszbek speaks at a public event with participation from Hungary's First Lady and national celebrities

not want people to switch off immediately the TV. We knew it should not be gloomy and dark. At the same time we didn't want to evoke in people the hope that hospice care was just a phone call away—because there were almost no hospices in Hungary.” In the end, the spots were “emotional but also thought-provoking, straightforward but gentle.” The actors spoke “about how difficult it is to die, how difficult to lose someone we love, but that it is even more difficult if the circumstances are very poor...How much better it can be if people are able to love and be at the bedside of that person to the very last moment.” And how all that is possible: with hospice.

At the same time, the campaign put up 100 billboards, ran print and Internet ads, and, in café restrooms across the country, put up posters showing the beautiful, but obviously ill face of a 24-year-old man with Hodgkin's disease and lymphoma. The text was an excerpt from a poem “saying that the dignity of life must last until the last minute of life.” The ads inspired lively and searching conversations among the young denizens of the cafés. Public awareness got another big boost when the advocates gave an address to the Hungarian Parliament; their press conference drew 40 to 50 Hungarian media outlets. That event generated over 100 TV, radio, and print media inter-

views throughout the following year. Professional awareness climbed, as did requests for collaboration.

By the end of the campaign, awareness of the word *hospice* had grown from zero to 36 percent. Muszbek gives an example of just how widespread the effects were. “I was in the market buying some papers and I asked for the receipt made out to the Hospice Foundation.” The clerk, a woman of 22 or 23, “with dyed hair and long painted fingernails,” recognized Muszbek from her appearances in some of the TV spots. “She said, ‘Oh, you are that person who is doing that wonderful work.’ Tears were coming into her eyes. She told me, ‘I wish you all the best and all the success.’” Says Muszbek: “I met this kind of phenomenon very, very often.”

A Positive Turn

The immediate goal of the Hospice Foundation was to renovate the Budapest kindergarten. Donations were raised from companies, foundations, and individuals. Because of the campaign, “they knew what we were doing, and they knew [its] meaning.”

The publicity campaign also opened the doors to talks with health care decision makers. In 2004, minimum standards for palliative care were passed and the Ministry of Health agreed to finance hospice and palliative care services. Today, the number of hospices has grown to 210 beds and 32 home-care services throughout the country. There is still a long way to go: only around 15 percent of dying cancer patients are in hospice—“but a couple of years ago it was 2 percent,” notes Muszbek. The next step is integrating palliative care into medical education, where it is yet to have a presence.

Hungary’s palliative care program has benefited from the support of the Open Society Foundations since its inception in 1991, when an advocate attending a dinner party hosted by George Soros asked him for help. That vote of confidence has been recast over the ensuing years: since 2000, Hungary has been supported as a resource center.

Today, Budapest Hospice House is a palliative care Center of Excellence, offering education to health care providers in the region. For many of these participants, their visit to Budapest is the first time they have been inside a hospice or palliative care unit. In the past few years, Muszbek and a colleague have mentored health care professionals in palliative care development in Georgia, Moldova, Turkey, and Ukraine through training and advocacy in the ministries and Parliament. Hungary was the host of the 11th European Association for Palliative Care (EAPC) congress in 2007. At this congress, Soros received an award for his contributions to the development of palliative care worldwide.

As part of its advocacy in the region, Hungary freely distributes its 2001 media campaign package to any country that wants to adapt and use it.

But the work of engaging the public is hardly over inside Hungary’s borders. “Our own experience in Hospice House is that the awareness we have in Hungary is still not enough. The people still are afraid of death and dying.” Families refuse hospice care, says Muszbek: “They think if they do not go to hospice, they have hope that they will be cured.”

Fields of Hope

“The people need to know that death belongs to normal life,” she continues. “We are born, we live, and we die.” To inculcate this message, Hungary’s advocates are working with the next generations. In kindergartens and elementary schools, children are learning through art, sports, and trips to the zoo about the naturalness of death and the importance of tenderness and dignity at the end of life.

One activity is planting flowers in city and village squares, part of a 60-year-old international palliative care awareness and advocacy campaign called “fields of hope,” whose symbol is the daffodil. When the flowers bloom in spring, they are greeted with celebrations and fundraising events for hospice and palliative care. Muszbek says she carries a vision of Hungary 10 years from now: “All the main squares will be yellow with daffodils, symbolizing hope and the dignity of life.”

Fields of Hope, Hungary



Unity through Communication: The CEE & FSU Newsletter

Launched in 2005 by the Hungarian Hospice-Palliative Association, with support from the Open Society Foundations and the European Association for Palliative Care, the Central and Eastern Europe/Former Soviet Union (CEE & FSU) Monthly Palliative Care Newsletter defined its goals this way: “to communicate the activities, diversity, challenges, and progress being made in palliative care development; to foster networking, communication in Central and Eastern Europe and Former Soviet Union; and also to inform those throughout the world about the regional effort.”

But its editor-in-chief, Katalin Hegedus, MD, president of the Hungarian Hospice Palliative Association, says she had more specific aims: “my favorite vision” for the newsletter, published in English and Russian, was to bring more Eastern and Central Europeans to the biannual congress of EAPC, on whose board she serves. With 18 years of palliative care under her belt, Hegedus also serves as associate director of the Institute of Behavioral Sciences at Semmelweis University in Budapest. She knew that once they attended the conference, they would be better armed with the knowledge, contacts, and inspiration to hasten the progress of palliative care in their countries.

Hegedus's goal seems to have been soundly realized. In Germany in 2005, 90 people attended the congress from the region. In 2009 in Vienna, that number grew to about 3,000 people from more than 80 countries. In addition, of the EAPC's 50 "collective"—or national association—memberships, 10 are now from Eastern Europe. Before the newsletter, the region accounted for only three.

A recent newsletter's articles range from abstracts for the EAPC conference and an announcement of a project to establish Belarusian-Latvian cooperation in children's palliative care to photographs of Hungarian children planting daffodils and a report of a scenic train ride raising funds for BELhospice in Belgrade, Serbia.

Most important, says Hegedus, the newsletter alerts readers to grant opportunities to attend conferences and trainings and otherwise advance palliative care in their nations. For instance, she recently met a doctor from the Czech Republic who found the application for a Salzburg Seminar in the newsletter and was accepted to attend. Many palliative care workers have been able to attend EAPC congresses after reading about available congress grants from organizations like Help the Hospices.

The newsletter goes to 1,200 email addresses, where about 500 to 600 readers regularly view it in English and about 50 in Russian (editorial board member and translator Elena Vvedenskaya says that few Russian hospitals and homes have computers). These readers live and work in 25 of the 28 former Soviet countries, as well as throughout Western Europe. Hegedus's plans for the future: to make the newsletter more interactive to facilitate networking and communication among regional leaders.

Spotlight on Implementation

Implementation might look like the end of the story: the stage at which a system has the policy, the drugs, the training courses, medical specialties, and licenses. However, before the implementation phase can take hold, a country must achieve the “buy-in” of opinion leaders and trained personnel on the idea of palliative care and their support for strategic and business plans, as well as standards and guidelines with which to evaluate the services.

Public health care provision always must grow and change to meet new challenges: new diseases, new demographic realities, new politics. And it must pay for all that.

Palliative care might be unique in public health in one regard: it is a service that can reach full implementation in hospitals, nursing homes, in-patient hospices, day care, and home care, and serve everyone, *affordably*.

Mongolia: Carrying Comfort Over Harsh Terrain

The developing world contains myriad stories of implementing palliative care over seemingly intractable obstacles. But Mongolia’s story is extraordinary, both for the magnitude of those obstacles and the success it has achieved. The country is well on its way to providing palliative care to everyone who needs it.

The Central Asian nation is sparsely populated, with only 2.8 million people dispersed over 1.5 million square kilometers. The weather is very hot in summer and very, very cold in winter. Rocky, snowy mountains cover the north and west; the Gobi Desert dominates the south and east. Much of the population—four in 10—lives in the capital, Ulaan Baatar.

Although foreign investment is increasing, economic growth has not benefited the vast majority of Mongolians: 36 percent live below the poverty line, 38 percent have no access to improved water, according to the World Bank.²⁶

And yet in these dry steppes and mountains, a high-quality, well-organized palliative care system is blossoming. The nation

has achieved all four of the WHO's foundation measures: policy, drug availability, education, and implementation—the stage at which a system has the solid backing of opinion leaders, a complement of trained personnel, strategic and business plans in place, and standards and guidelines to regulate and evaluate services. On the International Observatory on End of Life Care's global map of palliative care development, Mongolia is in the highest group, Category 4: Approaching Integration.

Part of the credit goes to a Ministry of Health in a government committed to social welfare. In spite of limited resources, Mongolia has virtually eliminated illiteracy. Health expenditures per capita in 2002 amounted to only \$128, yet the government vaccinates every baby within 48 hours of birth.

The rest of the credit for Mongolia's remarkable progress in palliative care goes to at least two indefatigable champions, the powerful will of the country's health care practitioners, and the concerted technical and financial support of the international community.

A Fast Buildup

Mongolia badly needs palliative care. Cancer is the second-largest cause of death, with a rate of 134 per 100,000 people, or about 3,740 new cases of cancer each year. Eighty-seven percent of these cases present late, 90 percent of these are incurable, and 70 percent of patients die within a year of diagnosis. Three of the most common cancers in Mongolia—liver, lung, and esophagus—present late and are incurable. Of the 11,700 Mongolians who die each year, it is estimated that 60 percent would benefit from pain relief with morphine.²⁷

Recognizing that palliative care was the humane and cost-effective response to these realities, the Minister of Health in 1995 invited Jan Stjernswärd, chief of the WHO Cancer Unit to come to Mongolia to review the situation. Members of the faculty of the Medical University and National Cancer Center in Ulaan Baatar were already keen on palliative care. In 2000, they founded the Mongolian Palliative Care Society (MPCS). That year, as well, the National Cancer Center opened a palliative care department. The person who spearheaded this activism—the first champion—was a family doctor named Odontuya Davaasuren. She became the society's president and has continued to lead the country's drive towards integrated palliative care.

In those early years, the Open Society Foundations supported MPCS in its advocacy efforts within the government and popular media. Continuing its grant-giving, the foundation supported Davaasuren and the MPCS as they began integrating palliative care into health care education, translating the field's major international texts and developing new handbooks, and opening the first hospices and palliative care units. Davaasuren traveled the country, training as many doctors as she could.

Participation in IPCI's 2003 Palliative Care Policy Development Conference in Budapest gave Mongolia an important push. One participant at the conference was the WHO's Stjernswärd. "Mary Callaway said to me, 'Won't you go to Mongolia?'" recounts Stjernswärd. "I knew that things were already functioning there. And that I can't do this without a champion." He started working with Davaasuren. "She right away got all the right people in. And they had very good people, despite the country's political ups and downs."

From 2002 to 2006, a leadership team including Davaasuren and Stjernswärd, and other Mongolian health care professionals and high-level members of the Ministry of Health and WHO Mongolia, worked to establish a national palliative care program on the basis of the WHO foundation measures. One person who joined up around this time was a student of Davaasuren's, Gantuya Tserendorj, who would become another of Mongolia's most effective champions.

“They Came in Droves”

Policy reform and essential drug availability were secured, and the laws were changed so that family doctors could prescribe generic morphine. After that happened, San Diego Hospice's Frank Ferris and Mary Wheeler, a nurse from Capital Hospice in Fairfax, Virginia, gave Mongolian doctors their first bedside training in pain control.

Ferris describes what happened: an experience not unlike those he'd had in other developing countries. “Here are the doctors who see all these patients with advanced, incurable disease. They want to do something for their people, but they have nothing to give them. They almost have to become inured to all that pain. Then suddenly along comes these folks who say, ‘We can help you with that.’”

“They came in droves,” he says. “Really bright doctors and nurses hungry for facts and skill-building.” In these providers Ferris sees the main ingredient of Mongolia's rapid success: “the incredible will to help patients.”

Education continues apace. Today all of the country's medical universities and colleges offer curricula and training in pallia-

tive care. It is a required element of postgraduate education in 14 medical specializations, and since 2005 it is a licensed subspecialty for doctors and nurses. Tserendorj, who now heads the Cancer Center's palliative care department, has become a leading trainer, traveling to regional oncology centers and doing on-site education. The first palliative care social worker attained qualification in 2008.

Palliative care is now integrated into the health care system. In 2005, the Ministry of Health ordered that five palliative care beds be provided in each regional and district hospital, and the government started financing the National Cancer Center's palliative care department. But because the distances in Mongolia are so great—a medical center is typically 100 kilometers from a rural village—80 to 90 percent of Mongolians die at home. The exceptions had been cancer patients, who often received chemotherapy and other aggressive, often futile treatments at the cancer center and died in the capital, far from their families. So Mongolia has established numerous home-care programs and plans to add more.

As in most of the developing world, financing is the biggest impediment to building a full-scale system. Positive cost shifts from acute care to palliative care are helping the health care budget. This has enabled Mongolia to devote resources to cancer prevention and treatment for those it will truly help. The Cancer Center sees people mostly with curable disease. Meanwhile, the country has set the goal of preventing one-third to one-fourth of cancers, committing three percent of tobacco tax revenues to health care. Prevention will take many years to start proving itself, but palliative care “starts working today,” says Stjernswärd. He believes that the prevention goals can be reached, and so can those for palliative care: “All cancer patients will get relief from pain within two to three years. We should be very optimistic.”

Politics and Palliation: Georgia, Moldova, and Ukraine

Political instability often leads to new obstacles to implementing and sustaining palliative care. A dearth of civil and human rights, frequent changes in administration, poor communication between government ministries and NGOs, and limited citizen power in pushing for policy change are common problems in countries with nascent palliative care movements.

“The overriding principle is political will and leadership,” says IPCI Director Mary Callaway. So “each time there’s a new administration, for example in Moldova and Georgia, we have

Medical professionals attend a palliative care seminar in Moldova



to start over from scratch: a new national commission, a new concept paper, a new palliative care plan, and a new stakeholders group” who must be persuaded to buy in to palliative care.

The story of progress in Moldova perfectly illustrates the case at point. The palliative care leaders have worked tirelessly for the last several years with stakeholders and government officials to create and recreate the necessary task forces and commissions to develop and redevelop the palliative care policy framework. The adage of two steps forward and three steps back readily applies. But within the past few years, real progress has been accomplished and the hope for complete palliative care integration seems achievable. Moldova’s parliament has approved the national concept for palliative care. The National Cancer Program, based on the WHO Recommendations, was approved by the Ministry of Health and includes palliative care. A written request was submitted to the ministry by the country’s chief oncologist and pharmacologist as well as the Association of Pharmacists to revise the essential medicines list to include oral morphine. The regulations and bylaws on the organization of palliative care services were developed and approved by the ministry. The ministerial order controlling the prescription and delivery of medicines has been reviewed by the Oncology Institute, the Drug and Medicines Agency, the National Standing Committee on Drug Control, and the Association of Pharmacists and is now finally awaiting approval. Amendments to the law regarding the circulation of narcotics, psychotropic substances, and precursors is also now in the parliament for approval.

Palliative care professionals and advocates in Moldova are not standing by idly as the necessary policies for palliative care development are drafted and redrafted. They have worked with the director of the National Oncology Institute to get a mobile

palliative care team developed; they have created and strengthened a national association for palliative care; they have developed clinical protocols on chronic pain, symptom control, and skin care; and they have trained dozens of physicians and nurses and gotten a palliative care curricula for nursing integrated into many medical colleges in the country.

In Georgia, palliative care support and development has drawn the attention and leadership of the First Lady of the country as well as a handful of dedicated advocates and palliative care professionals. At a time when the political leadership of the country is under attack, the inspiration and leadership of the First Lady who is a trained nurse and volunteers weekly in the palliative care department elevates the need for palliative care onto the national agenda. In 2008, an inpatient unit was developed in the Cancer Prevention Center and staffed by a multidisciplinary team. The success of this program led to the recognition that palliative care services should be available to patients receiving care at the National Cancer Hospital and out of this grew the first inpatient palliative care consult service and inpatient unit in a cancer hospital in the region. This commitment to integrate palliative care into a national cancer hospital will surely serve as a model for other oncology hospitals in the region.

But cancer patients are not the only patients in need of palliative care. The Global Fund to Fight AIDS, Tuberculosis and Malaria is supporting palliative home care services for AIDS patients in three areas of the country. These initiatives focus on the development and delivery of palliative care mainly for adult patients but there is an enormous need for pediatric and geriatric palliative care as well. Although the development of inpatient and home care services draws the most public attention, the education and training of palliative care clinicians is also

moving forward and lectures on palliative care elements are now included in the medical and nursing school curriculums.

One of the acute problems affecting patients under palliative care in Georgia is related to legal consequences following their death. The country's palliative care centers are largely unable to provide patients with proper legal services. In other words, adding to the physical pain of a dying Georgian and the anguish of her family is anxiety about practical issues like inheritance and care for dependants. The Open Society Foundations Public Health Program is tackling this problem through an innovative initiative that links legal services with palliative care programs. The initiative goes further than simply establishing connections to lawyers; it also trains hospice staff and provides them with resources on the primary legal issues faced by patients and families. Having this basic knowledge helps the hospice staff to know when and where to refer patients and families in need of legal help. At the same time, human rights and patients' rights advocates in Georgia are working for policy changes to bring Georgian law in line with international standards for health care, including palliative care. In addition, the Open Society Foundations Public Health Program has produced guide books on human rights in patient care for lawyers and health care professionals, as well as patients and their families.

Sometimes unspoken, sometimes explicit in these impressive reports and plans are the obstacles to implementing and sustaining palliative care that are presented by political instability: a dearth of civil and human rights, frequent changes in administration, poor communication between government ministries and NGOs, and limited citizen power in pushing for policy change. In Ukraine, says Callaway, after years of advocacy and slow progress, "seemingly overnight, the government decided they wanted palliative care." The government

welcomed recommendations from civil society organizations like the All Ukrainian Palliative Care Association and the All Ukrainian Council for Patient Rights to make opioid analgesics more available to patients suffering with chronic diseases. The government also responded with the creation of the Institute of Palliative Medicine and charged it with palliative care development throughout the country.

Ensuring essential medicine availability and revising the legal framework for the implementation of palliative care were only the beginning for Ukraine. The leadership of the National Medical Academy for Postgraduate Education immediately recognized the need to educate practicing physicians as well as medical students. An international faculty delivered a three-week bedside training program for physician nurse teams from 15 clinical sites throughout the country. This training led to the Minister of Health establishing a working group to develop a government approved palliative care curriculum to be used in all medical universities. And while policy and education components were being worked on, services were already starting to deliver care. This is the strategic key: identifying the leverage points and balancing the work carefully on several levels (policy, drug availability, and education) at the same time.

Without a doubt, these three elements are essential but having a model program for all to see and understand is perhaps the most critical component for success. And a model program created by a charismatic leader who goes into government in a position of influence is about as good as it gets. Ukraine's Ivano-Frankivsk Hospice is such a model program. Founded years ago by a member of the Ministry of Health, the 30-bed inpatient hospice now enjoys an oblast-level hospital status, is financed from the oblast state budget, licensed to purchase, store, and prescribe narcotic analgesic drugs, has a qualified

staff, and serves as a clinical training site for both medical and nursing students. "The political drive for palliative care can come on quite suddenly," says Callaway. "A minister's mother or wife dies of cancer, in pain, and the light goes on."

The strategy of the international palliative care community, including IPCI and the WHO, is to build effective, integrated palliative care by putting policy on the books and systems in place that can be sustained through political changes and rocky periods. After all, people get sick and die regardless of who is in power.

Monitoring the Progress

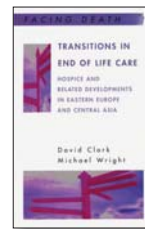
The humanitarian value of helping people live with complex illness and die with dignity and comfort may seem self-evident. But beyond that, providers and funders must continuously examine their practices: *Are they doing the right thing—and if they are, how is it working? How much is being invested in money, time, and human labor, and with what results? Are opioid analgesics available, accessible, and affordable? Are programs being established, and are they adhering to high standards of practice? Are care workers being trained and accredited, and are standards of practice being adhered to?*

Scrupulous evaluation and monitoring of progress—both in quantitative measures and through qualitative testimony of patients and professionals—are necessary whether the object of assessment is an individual nurse or doctor, a local hospice, a national system or international funders, researchers, and advocates.

That last object of scrutiny—global palliative care development, both overall and broken down by countries or regions—is of particular importance for both advocates and the international organizations that support them.

The International Palliative Care Initiative supports numerous institutions and collaborative projects that engage in the ongoing monitoring and evaluation of palliative care development worldwide.

Mapping the World: The International Observatory on End of Life Care



Like many projects of the International Palliative Care Initiative, the International Observatory on End of Life Care (IOELC) was born out of a conversation between IPCI Director Mary Callaway and an advocate or researcher in palliative care: in this case, David Clark, then professor of medical sociology at Lancaster University's Institute for Health Research in England. "We were in Croatia in 2003," recalls Clark. "We were talking about creating benchmarks . . . to see where [countries] are vis à vis their neighbors and use those ratings to advocate for additional resources. I said we could create a map for the 28 former Soviet countries in Eastern and Central Europe. And Mary said, 'David, that's too limited—the whole world needs this kind of information!' That's when we created the IOELC," which Clark founded.

The IOELC's "aims are to provide clear and accessible research-based information about hospice and palliative care provision in the international context" and disseminate it via its website, other publications, and the media, "in ways that facilitate cross-national comparative analysis and stimulate practical development."²⁸

The IOELC developed a four-part typology depicting levels of hospice and palliative care development: Level 1: No Known Activity; 2: Capacity Building; 3: Localized Provision; and 4: Approaching Integration. Using data from its own literature reviews, interviews, surveys, databases, and other sources, IOELC has created a global map of palliative care development in the 234 countries recognized by the UN, in six major regions.

The map shows many things, but one most glaringly: development globally is “patchy” at best, with only 35 countries—or 15 percent—qualifying at having achieved Level 4 and 78 evidencing no activity at all. Unsurprisingly, palliative care development is correlated with other measures of human development, and with income. Among those at the highest level, most are in highly developed countries. Only one in Level 4, Uganda, is categorized as a “low-development” country on the UN’s human development index, a measure based on longevity, knowledge, and standard of living. It is fair to say that part of Uganda’s success can be credited to international development, including support from IPCI. This is also true of other resource-limited countries that have reached the higher levels of palliative care development.

Most important, says Clark, are the in-depth reports of over 60 countries. In these reports, “we try to drill down in depth, talking to key people, gathering together gray literature” with the scientific reports, “to look beneath the headline at what we can learn about the character and development of palliative care, policy, and services in each of those countries.” Interviews provide rich narratives of how countries organize palliative care programs in ways that conform to the WHO public health strategy, while at the same time respecting local traditions and histories.

The observatory provided information at a time when there was very little to be had, enabling people to meet each other and networks to form. Experts traveling to a country they didn’t know could quickly glean a picture of its population, epidemiology, political economy, and ethnographic makeup. In the early years, “people used our reports to find out about what was happening in their own cities!” Clark says.

As an advocacy tool, IOELC’s data continue to help proponents of palliative care to go beyond rhetoric. “We are seen as the honest brokers of information. [Ours is] a picture, warts and all—a reliable and reasonably objective source of information.” The observatory’s in-depth investigations of the countries of Eastern Europe and Central Asia led to the book *Transitions in End of Life Care: Hospice and Related Developments in Eastern Europe and Central Asia (Facing Death)*, by Clark, Michael Wright, and Jacek Luczak. The book looks at the development of palliative care in the post-Soviet era and identifies both the keys to success and the obstacles to improvement.



A similar project, which grew out of the mapping of 47 African countries is *Hospice and Palliative Care Development in Africa: A review of services and experiences*, also by Wright and Clark, along with Jenny Hunt and Tom Lynch. That book was funded by the Diana, Princess of Wales Memorial Fund and the

Elton John AIDS Foundation.

One problem that faces the IOELC—both a sign and a burden of palliative care’s rapid progress—is the quixotic task of keeping its information current. IPCI provided support to IOELC in 2006 and 2007 to update its data on the countries of Eastern and Central Europe, Central Asia, and the former Soviet Union. But the team is fairly sure that similar efforts are not in the

cards for all of the reviewed countries. “We’re asking, how sustainable is that work, and if so, where to do it?” Clark says.

One new way to “do it” is to focus not only on the countries in need of development but also on the organizations stepping in to help them achieve their goals. Initiated and supported by IPCI, the IOELC produced a donors’ study, reviewing the global picture in giving to palliative care development.

Measuring Pain Relief: A single Metric for Opioid Consumption

Opioid consumption is a valuable indicator of where a country stands in delivering pain-relief medicine to people who need it. Before 1986, when WHO published its Three-Step Ladder for Cancer Pain Relief, measuring morphine consumption alone made sense, because that was the drug used for pain, almost exclusively, everywhere. Since that time, though, pain-control knowledge and experience have increased, more types of opioids have been developed, and they are administered in more complex manners and combinations. The Pain and Policy Studies Group (PPSG), which regularly publishes data on drug consumption, has found wide disparities between countries. But the statistics have been cumbersome and inaccurate because of the differences in types and strengths of analgesics.

IPCI has supported the group in mapping country-specific information about drug availability and consumption and in making this and other information easily accessible on its website.

Now IPCI is supporting PPSG to work with the WHO Collaborating Center for Drug Statistics Methodology based in Oslo, Norway, in creating a single metric for studying opioid consumption. The metric is an algorithm, a mathematical calculation that combines the reported consumption of all the principal opioids used for severe pain, in their varying strengths. It produces a numerical value by which the consumption of different countries (or states or institutions) can be uniformly, accurately, and efficiently assessed and compared. In one of the metric’s initial trials, the researchers applied the metric retrospectively to the PPSG database. They found that wide global disparities persist, with the 20 top reporting countries still consuming almost 90 percent of pain medicines.

The measure has some limitations, says Martha Maurer, Senior Policy Analyst at PPSG, who is working on the project. For instance, some opioids have clinical indications other than analgesia, such as for anesthesia or to treat heroin addiction, so a gram of consumption does not always equal a gram of pain management. Nevertheless, Maurer says she and her colleagues are optimistic about the potential of the new metric to standardize global measurement and are working on better ways to capture and decipher the necessary data.



A doctor travels to rural communities in Kenya to provide palliative care services

The Future of Care

What lies ahead for global palliative care development? In one sense, more of the same—with the emphasis on *more*. More programs, more patients, more places, more drugs, more funds. Continued palliative care development will be needed not only to catch up with current needs but also to contend with what is ahead: aging populations worldwide, an ongoing HIV/AIDS pandemic, and a predicted sharp increase in new cases of cancer—a 50 percent jump, to 15 million, by 2020, largely fueled by growing cancer rates in the developing world.²⁹

The challenges go far beyond numbers. To fulfill the promise of palliative care, advocates, practitioners, governments, and funders must do nothing less than change the culture of dying and death, both within medicine and in the larger world.

In many countries, the word *death* is hardly ever spoken—at home, in the hospital, at school, or on television. Many people in the United States or Europe have never seen a person die. Palliative care, with its roots in hospice, begins and ends, in a sense, with contemplating death, with coming to terms with it, learning how to accept it and at the same time to relieve the suffering that may attend it. Palliative caregivers, with long experience and wisdom in this area, can stimulate and influence the conversations that need to be had.

In order to build widespread support from the public, medical providers, and policymakers, palliative care professionals need to find ways to integrate not just their services into the system, but also the *values* of palliative care into the culture.

The Aging: Meaningful Life until the End

In spite of the alarming slide in life expectancies in countries affected by HIV/AIDS, the average age at death is climbing globally. The UN estimates that the number of older people (60 and above), will more than triple globally by 2050, to a projected 2 billion. Among these, the very oldest (80 or more) will grow from 11 percent to 19 percent, with the number of centenarians increasing 15-fold, to 2.2 million.

It is not clear whether longer lives necessarily mean longer periods of disability, yet if people keep dying from today's fatal chronic illnesses—such as heart disease, cerebrovascular disease, respiratory disease, and cancer—they will need more care. As well, chronic conditions such as dementia, arthritis, and osteoporosis, which tend to affect women more, will add to

Best Practices for the Elderly



In 2004, the WHO Office for Europe published *Better Palliative Care for Older People*, edited by Elizabeth Davies and Irene J. Higginson, a frequent IPCI collaborator. The document discusses the demographics of aging in Europe and the needs and rights of older

people and their families. It presents evidence for effective solutions to the challenges facing health care systems in delivering palliative care to the elderly. Recommending an integrated public health approach, the booklet proposes rigorous research into geriatric palliative care needs and methods; commitment to ongoing quality improvement; adequate funding; up-to-date professional training; and social changes such as combating ageist stereotypes. IPCI, which provided early financing and support for the report, also funded its dissemination and Russian translation.



A companion booklet, *Palliative Care: The Solid Facts*, expands on the evidence and serves as a “best practices” guide for policymakers and the public. IPCI supported the production of a second *Solid Facts* booklet that presents best practices in palliative care for the elderly.

the burden of end-of-life care. And by 2030, people over 85 will represent 44 percent of deaths, up from 32 percent in 2004.

Aging in Africa

Of the world’s elderly, six in 10 now live in resource-constrained countries, and that number is expected to grow to eight in 10 by 2050. The majority of these older persons are women.³⁰ Besides being slowed down by the ordinary disabilities of aging, many of these elderly live with untreated pain. Their troubles are compounded by poverty—inadequate housing, food, clean water, transportation, and health care generally. Instead of being cared for in their old age, the AIDS epidemic forces women to become caregivers to their own sick children and raise their orphaned grandchildren.

“Bridging the Gap: Extending palliative care services to older people in two East African countries” is a study of the life experiences of the elderly in Kenya and Uganda and a review of current services and unmet needs. Rich in the voices of the elderly, their caregivers, advocates, and palliative care professionals, it details the challenges the ill face in these two countries, from loneliness to lack of rent money to incompetent health care.

“Bridging the Gap” makes recommendations for the future integration of palliative care into existing services for older people in Africa, including the community partnership model pioneered in South Africa. The study was undertaken by the Ugandan-based African Palliative Care Association (APCA), a major Open Society Foundations grantee, and funded by the UK-based Help the Aged. The Kenyan Hospice and Palliative Care Association, the Palliative Care Association of Uganda, and Nairobi Hospice also worked on the study.

Women: Everyone's Carers, Uncared For

The future of palliative care, like its past and its present, will have women at its center.

“Women hold up the bulk of community health care programs,” says Faith Mwangi-Powell, the Kenyan-born director of the African Palliative Care Association. “At the same time they must care for their husbands, their children, and their grandchildren. Caring is a women’s job. It has no prestige. And yet, when women have illnesses themselves, they have no one to care for them. That,” she says, “is the double jeopardy for women.”

Women do indeed have illnesses—especially AIDS. According to 2007 WHO and UNAIDS estimates, globally about as many women as men are living with HIV: 17.5 million women. Four out of five of these women live in Sub-Saharan Africa, where they constitute 61 percent of the people living with the virus. Because of their biological and social vulnerability, girls and young women age 15 to 24 are three times more likely to be HIV-positive than young men their age. Elsewhere in the developing world, HIV is also hitting female populations hard. More than half of adults living with HIV in the Caribbean are women, and new infections among women are rising rapidly in Asia. In the United States, black and Hispanic women account for a growing number of HIV cases.

Violence and Property

Why are women in this situation? Defilippi of the Hospice and Palliative Care Association of South Africa answers in two words: “Gender inequality.” She explains: “Women and girls have really got no say, particularly in negotiating safe sexual practices, or in nutrition and education. If it’s a very poor household, the last person to eat will be the girl child: first the men eat, then the boys, then adult women, then little girls.” If their mothers are sick, those little girls are their families’ caregivers.

Violence against women and tribal inheritance traditions additionally vex women and girls dealing with AIDS. In Uganda, for instance, although the law enshrines the right of women and children to inherit men’s property, clan and tribal elders often usurp that decision, with catastrophic results. Mwangi-Powell tells such a story. “There was a woman from Congo married to a Ugandan. They both had HIV. She took care of the husband, and he died. The family of the husband accused the woman of bewitching the husband. They drove her from the home and left her with five children, homeless.” Her eight-year-old daughter became a sex worker, another is now pregnant, and a third has died. The family is now living in a hospice, which cannot afford to keep them. “We are not adequately prepared for these huge, multiple social issues,” says Mwangi-Powell, adding, “The women have to deal with it all.”

Defilippi adds, “We need to provide every support we can to make gender equality an advocacy issue” in palliative care.

“As Women First, Then as Nurses”

“Many of the issues of what it is like to be a nurse are related to what it is like to be a woman. In many areas of the world, nursing is predominately female and medicine is predominately male, and nursing is dominated by medicine. So a real issue is the power women have as people—the lack of respect for their knowledge or independence—as women first, and then as nurses.

“On the other hand, people trust nurses. Often the nurse’s role is to be out there in the villages to say, ‘You really do need to take these pills.’ With the doctor, the patient will nod and say yes, go home, and listen to the people in the village who say that a terrible spell will be cast upon you if you take the pills. But when the nurse says ‘You need them,’ they take the pills.”

—Betty Ferrell, *End of Life Nursing Education Consortium*

The Trouble with Volunteers

Palliative care systems that integrate formal and informal health care networks have the potential of bettering women’s social and economic standing. But a system that relies on volunteer labor also risks further exploiting women, who comprise the lion’s share of volunteers. “If these women get some training or skills, no matter how limited the skills, that increases their social standing,” says Defilippi. “If they are just wiping the brows, their power decreases—they are the lowest of the low. The volunteers we have worked with, for instance in Kenya, get workshops and training, certificates and uniforms, training. That gives them a lot of status in the community. But status doesn’t put food on the table.”

Both Mwangi-Powell and Defilippi strongly support paying volunteers in cash stipends or food allowances. Since minimal government health care budgets now limit or preclude such payments, a more realistic expectation is that NGOs should provide these funds.

In a 2008 *British Medical Journal* editorial following the Global Forum on Human Resources for Health in Kampala, which called for action to resolve the shortage of health workers around the world, Mwangi-Powell put these ideas into the context of the worldwide health workforce crisis. African health organizations should “view [volunteers] as a potentially new cadre of health care workers, rather than an underappreciated adjunct to traditional health professionals,” she said, educating them more rigorously and accrediting them with “assistant” status. “Focusing on this cadre in the mid-term, with longer-term planning dedicated to more highly trained staff, would enable countries to scale up their critical mass of trained health

workers cost effectively and provide better quality services to deprived rural African communities in a shorter period of time.”

International health and women’s organizations, including the World Health Organization and the UN Development Fund for Women (UNIFEM), speak frequently of “mainstreaming gender” in public health policy—making gender equity a legal requirement of health care programs and including gender issues in professional guidelines and standards, curricula, and advocacy. But such mainstreaming is more than legal or even economic. It is cultural—and intimately related to the “mainstreaming” of palliative care, because the virtues of such care are often culturally and professionally devalued, implicitly if not explicitly, as “feminine.”

Indeed, women bring many strengths to health care, says Mwangi-Powell. “They bring compassion. They have the ability to see beyond the problem to the person. Beyond the HIV/AIDS, you see the husband, the son or daughter—the human being behind the suffering.” In Sub-Saharan Africa, palliative care organizations are making an effort to train more men—which implicitly means teaching them these “feminine” skills.

Compassion, meticulous attention, patience—seeing the total person and attending to her “total pain”: these are the fundamentals of caregiving and those of palliative care. Bringing these values and practices into mainstream health care, rewarding them financially, and encouraging and training men to share them can take the best of what women have to offer and also lighten their load as caregivers and as patients, mothers, wives, community members, and professionals.

“Compassion, meticulous attention, patience – seeing the total person and attending to her “total pain”: these are the fundamentals of caregiving and those of palliative care.”

“Children Came Last”: Pediatrics, Catching Up

The need for pediatric palliative care is great, especially in resource-limited countries and especially for children with AIDS. UNICEF reports that around the world, about 2.3 million children under 15 are infected with HIV, 90 percent of whom live in Sub-Saharan Africa. Most of these children contract the virus at birth or from their mothers' milk. Fewer than one in 20 has access to treatment, and up to half will die by their second birthday. Every day, another 1,800 children are infected, and as many die of AIDS.

Millions of these children have already lost parents to disease. Sub-Saharan Africa alone counts 12 million AIDS orphans, according to the UN, and by 2010 that number is expected to reach 18.4 million.

The toll of disease is increased by ignorance and prejudice. In Vietnam two-thirds of palliative care programs serve children with cancer or AIDS. Yet that country's 2005 Rapid Situation Assessment found that only a quarter of the program managers believed that children can suffer from depression, and a third thought children do not feel as sad as an adult does when a relative dies.

Many South African customs acknowledge a feeling for the tenderness of children. If a child is dying, the news must be whispered in her ear while she sleeps. Yet a motherless, HIV-positive three-year-old South African boy was locked in a shed for three months while his father traveled 400 miles away to work. The neighbors fed the boy through a window, enough to

keep him alive, but they did not report his abandonment for fear of retribution from the father.

Special Needs, Ordinary Needs

Appreciation of the problems and needs of ill and dying children is growing in the health and palliative care communities. The WHO has promulgated an official definition for children meriting pediatric palliative care. It includes children not just with “life-limiting” illnesses (as in adult definitions) but also with “life-threatening” ones, such as severe disabilities requiring serious interventions and diseases that might be cured, including earlier-stage cancers. The guidelines also recommend age- and weight-appropriate dosages of medications.



Hospice Casa Sperantei in Brasov, Romania, serves patients of all ages, including children

But Marston, who is a world-recognized authority on pediatric palliative care and founder of St. Nicholas Children's Hospice in Bloemfontein, South Africa, speaks of children's special needs in a different language than that of the WHO. The essentials of palliative care for children, she says, are food, love, and play.

"Play is a child's work," says Marston. "It is how they grow, develop, and learn." In the poorest families, the exigencies of survival get in the way of this basic need. Often a child with HIV is "cared for by sick parents or grannies, who are so involved in getting a roof over the child's head and food on the table that they cannot stop and play."

At St. Nicholas, says Marston, "we work to build resilience in the child." That work includes strengthening a sense of roots and memories, especially for children whose parents are dying; building understanding, acceptance, and respect of the self; and inculcating hope for the future. Hope is the hardest part. "With little children, give them lots of love and food, and it's easy. A child can be playing in the garden in the morning and dead in the afternoon. They still have hope," says Marston. But with teenagers, "that can be a very difficult intervention," made even more difficult "in a society in which children are orphaned, education is insufficient, and there aren't jobs to do." She adds that religion is central in South African life: "At least they have hope for a better future in the afterlife."

A major obstacle to good palliative care for children—both in the developed and the developing world—is the notion that children cannot understand death and don't need help in bereavement. "The attitude is, 'they'll be fine,'" says Marston. "There's also a real fear of how to deal with the child's pain and suffering—so they deny it's there." Many also believe that children do not feel pain as acutely as adults and are more easily

addicted to drugs, so they are reluctant to prescribe sufficient opioids. At the same time, Marston says she meets professionals who feel they can't watch children suffering, so they don't want children in their palliative care programs. The field faces a shortage of professionals.

Moving Forward

But things are looking up. Vietnam's National Palliative Care Guidelines issued in 2005 contain a chapter on pediatric palliative care that provides dosing guidelines for palliative care medications for children, as well as an outline of the developmental stages of childhood and the special needs of ill and grieving children at every age.

At HPCA in South Africa, Marston has taken up the task of training mentors in pediatric skills, pushing to get practitioners qualified in pediatric nursing and palliative care, and working on a textbook for Africa.

Also in South Africa, the Wits Palliative Care program in Gauteng was founded in January 2005 at the University of Witwatersrand to develop and provide quality palliative care; train and increase the number of health care workers doing such care; establish a coordination mechanism between NGOs and the public health facilities at the district level; and engage in policy development and advocacy. In 2007, Michelle Meiring, MD, formed the first hospital-based pediatric palliative care team as part of Wits Palliative Care, and Wits was designated as a provincial Centre of Excellence. In 2009, Meiring moved to Cape Town to work with the pediatric palliative care program at the Red Cross Children's Hospital and is helping to create a virtual pediatric palliative care resource center.

In 2007, for the first time, IPCI held a Salzburg seminar devoted to pediatric palliative care. In 2008, with IPCI support, the Fondazione Livia Benini convened a meeting in Florence as a follow-up to the first meeting in 1993, at which guidelines for cancer pain relief and palliative care in children were drafted. Those guidelines became the standard of care throughout the world. The purpose of the 2008 meeting was to review medical advances over the last 25 years and draft recommendations for future funding priorities.

And the global community is starting to work together on children's issues. One promising sign is the International Children's Palliative Care Network, which was established in 2008 as "the official children's voice in the Worldwide Palliative Care Alliance," according to Marston, who is its chair. The network launched a website to raise awareness and coordinate advocacy—as the home page says, to "provide an online global 'one stop shop' [to] enable the sharing of expertise and information between children's palliative care practitioners; and increase the international evidence base for children's palliative care." A recent IPCI grant to the network supports participation of steering committee members at international conferences; production and translation of advocacy materials to distribute at relevant gatherings; and opportunities for peer learning and development among members of the international pediatric palliative care community through travel/study tours to model pediatric palliative care programs.

In the palliative care community, "children came last," says Marston. "It is only within the last year or so that the funders, as well as the governments and even the hospices themselves, have acknowledged that children are different, they have different diagnoses, and they require different skills. A great deal

still needs to be done, but people are noticing. I think we are moving forward."

In the life of one child, things are clearly moving forward. That is the boy in the shed. After three months, someone contacted a palliative care organization, which rescued him. "He was skeletal and traumatized" and utterly silent, recalls Marston, but care workers patiently brought him around. Now he is in foster care, going to school, and on antiretroviral drugs. Reports Marston, "He is fat and beautiful."

Palliative Care as a Human Right: The Nairobi Strategy

"Palliative Care associations have articulated a simple but challenging proposition: that palliative care is a human rights issue. The international human rights covenants and the discipline of palliative care have as common themes, the inherent dignity of the individual and the principles of universality and nondiscrimination."

So begins "Palliative Care as a Human Right," a paper that lays the philosophical, legal, and historical groundwork for advancing a campaign by the palliative care community. Launched and funded by the Open Society Foundations, the project was a collaboration with the Hospice Palliative Care Association—South Africa.

"Palliative Care as a Human Right" served as the basis for the creation of the Nairobi Strategy, named at the African Palliative

Care Association (APCA) Conference in 2007 to describe an initiative focused on advancing this concept. The strategy began with a survey that asked palliative care leaders worldwide about the idea of palliative care as a human right and the resonance it had in their countries. The Worldwide Palliative Care Alliance and the International Association for Hospice and Palliative Care then issued a Joint Declaration presented at the XVII International AIDS Conference in Mexico City in 2008, calling on governments and opinion leaders to acknowledge pain relief as a human rights issue, to support policies that allow access to medicine for pain, and to ensure that palliative care and pain treatment are part of health care education. As of the spring of 2009, more than 4,500 individuals and organizations have signed on. This effort continued to gain momentum with attention from Paul Hunt, the former UN Special Rapporteur for Health and Human Rights, in his 2008 report that identified palliative care as an issue of increasing importance to the human rights community.

Similarly, Human Rights Watch published its report, *Please Do Not Make Us Suffer Any More: Access to Pain Treatment as a Human Right*, focusing on the need for patient groups and hospice and palliative care services to demand pain relief as a human right, with the goal of persuading UN bodies to inscribe this right in their conventions. Human Rights Watch is also calling for the UN High Commissioner for Human Rights to conduct country visits to assess palliative care access and availability. These topics were discussed during an all-day session at the 17th International Congress on the Care of the Terminally Ill in Montreal in September 2008. Grantees of the Open Society Foundations led the discussions and described the approaches and opportunities in addressing palliative care as a human rights issue within the UN system. Diederik Lohman, from Human Rights Watch, was joined by Liz Gwyther and

“Many other right-to-health issues need urgent attention, such as palliative care. Palliative care includes pain relief for the terminally ill. Every year, millions suffer horrific, avoidable pain. Very few have access to pain-relieving drugs. As always, those in the developing world suffer much more than those in the developed world. Six countries account for 79 percent of medical morphine consumption. But this is not just a problem of development. Lack of access to pain relieving drugs is partly due to regulatory barriers. Regulations aim to protect populations from drug dependence. But these regulations do not always strike the right balance between this legitimate aim and genuine medical needs. In short, palliative care needs greater attention. Many HIV/AIDS strategies, for example, neglect this critical issue.

“11 October 2008 is the World Hospice and Palliative Care Day. The theme was ‘Palliative Care is a Human Right.’ I urge you to give this issue—and this Day—the attention it richly deserves.”

—Paul Hunt, UN Special Rapporteur, on the right to the highest attainable standard of health, March 11, 2008

Kathleen Foley, who presented various perspectives on this topic. Also in 2008, the World Hospice and Palliative Care Day declared palliative care as a human rights issue as its theme; its aim was to foster a broader engagement of the topic within the global palliative care community.

Philosophic and Historical Links

Adding palliative care to the struggle for universal health care—and doing so in the name of human rights—makes philosophical, legal, and historical sense. No human experiences are more universal, no equalizers greater, than illness and death. And there are no needs more universally human, especially in illness and death, than comfort, dignity, and the relief of pain. Answering these needs is at the heart of medical ethics, notes the strategy document: “[T]he ethics of the medical care of the patient with a life-limiting illness has a deep humanitarian core—of compassion in approach, meticulous concentration on symptom control, clarity and sensitivity in communication to the patient and family, guiding all through the unique journey of dying. If there is a clear ethical obligation to relieve suffering or act virtuously by doing so, one may argue that from that obligation springs a right.”

And yet, in another sense, death is not an equalizer; all deaths are not equal. As this report has shown, the poor suffer and die disproportionately of preventable and treatable illnesses, and they do so in more pain. Nor are comfort and dignity universally accessible or affordable.

The articulation of health care as a human right dates back two decades and has been reaffirmed repeatedly since. The principle was written into the first WHO Global Strategy for

the Prevention and Control of AIDS in 1987. Other international conferences, such as the 1994 International Conference on Population and Development and the 1995 Fourth World Conference on Women, reiterated it. In 2001 the UN Human Rights Commission called for the international recognition of an obligation to promote “the right to health” and the following year appointed a Special Rapporteur for Human Rights on the international right to health. The WHO continually makes explicit the connection between health and rights.

Although less firmly established, the concept of palliative care as a human right is not without precedent. For instance, in articulating the right to health care, a Comment of the Declarations or Conventions from the inception of the UN specifically refers to access to “palliative health services.” And the WHO’s advocacy for pain relief, which began with cancer care, led to the inauguration in 2004 of a Global Day Against Pain. The theme of the day was “Pain Relief Should Be a Human Right.” A panoply of international laws that have emerged in the last 20 years also stand ready to be deployed to enforce this young and untested right. They include laws against negligence and elder abuse and torture among others. In January 2009, Manfred Nowak, the UN Special Rapporteur on Torture, issued a report to the Human Rights Council in which he concluded that, “the de facto denial of access to pain relief, if it causes severe pain and suffering, constitutes cruel, inhuman or degrading treatment or punishment.”

The palliative care movement has been slowly writing its own history of a right to freedom from suffering from life-limiting diseases and end-of-life pain. In 2002, a conference of African palliative care trainers drafted the Cape Town Declaration in response to the paucity of care for their continent’s millions of AIDS and cancer sufferers. The declaration’s first assertion

was “palliative care is a right of every adult and child with a life-limiting disease.” Two years later, the International Working Group of the European School of Oncology stated that “there should be free access to palliative care ... for all cancer patients, as a fundamental human right.”

The 2005 Montreal Statement on the Human Right to Essential Medicines links universal access to necessary drugs with the international right to health care. The statement includes opioids for pain among those essential medicines. Demonstrating that such documents are not just rhetoric, the WHO took up the torch lit in Montreal and asked the International Association for Hospice and Palliative Care in 2006 to develop a list of Essential Medicines for Palliative Care. The Open Society Foundations co-funded the development of this list (see page 46).

Food and Medicine

A human rights approach has its weaknesses, its advocates concede, including an uneven embrace of a rights discourse globally, a lack of proven enforcement instruments, and the material limitations of many governments to deliver universal palliative care. That last weakness hits hardest in developing nations. When a government can barely provide its people with food and security, how can anyone argue that bereavement counseling, or perhaps even pain relief, is an inalienable right? The concept may sound so idealistic that it approaches meaninglessness.

Mwangi-Powell of the African Palliative Care Association expressed this truth movingly. “I am very excited to look at palliative care as a human right,” she declared. “But we always

have to look at the context. In Africa, the concept of human rights is debatable. You say it is my right to get health care. You go to hospital and there is not a bed, not even a paper to write a prescription on. So do you have a real right to health care? You have a human right to education. You go to school and there is no desk, no pencil, no teacher. You have a right to water, but there is no clean water to drink.

“If people don’t have food, what does this right—the human right not to be in pain—really mean?”

One way to confront this vexing question, both in theory and in practice, is to try to win it all at once—food, security, and freedom from suffering—by constructing them as one category: health. This is what the 2000 General Comment on the Right to Health of the UN Committee on Economic, Social, and Cultural Rights does. It states that the right to health includes not only appropriate medical care but also clean water, adequate sanitation, food, housing, and health-related education.

Palliative care providers in resource-limited countries have already made this link between providing health care and responding to the entirety of a person’s needs. It is the most logical, and humane, extension of the idea that palliative care is care of the whole person. On the global scale, the extent to which governments, economies, and philanthropies can bridge the gap between this expansive new right and the services that make it real is equal to the alleviation of “total pain” in its broadest, most tragic, dimension.

Whatever its weaknesses, the human rights approach offers palliative care advocates a new discursive framework and a plethora of political strategies and legal tools to advance the

cause. Equally important, alliances with the human rights and larger public health communities can multiply energy, knowledge, and resources, and add moral ballast and the fuel of optimism to the vessels carrying comfort and dignity to the ill and dying.

Advancing Palliative Care Globally: Priorities and Recommendations

Priorities

To sustain palliative care for the long term, progress must be made in terms both of structures and financing. To this end, the global community should adopt the following priorities:

- **Integrate palliative care into health care systems at every level.** Even in those developing countries that have palliative care, many if not most services are inadequate, scattered, and operating separately from the mainstream health care system. Palliative care must be available to all people who need it, when they need it, at a cost they can afford. This requires the *integration* of palliative care for patients and their families into health care practice at every level, from the national hospital to the local clinic to the home bedside.

Integration means that palliative care is a mandatory subject of study for every medical, nursing, or other health care-related student. That morphine for pain becomes as automatic—and legal and accessible—a prescription as

antibiotics for infection or insulin for diabetes. Integration means that whenever someone is dying, she and her family can be assured that her last breath can be taken under the ministrations of a palliative care worker, in a hospital, hospice, or at home, in comfort and with dignity.

In 2007, the World Health Organization published a series of six modules that offered recommendations on cancer control planning. The module on palliative care explains how countries can develop effective palliative care programs within the context of a national cancer control program in low, middle, and high resource countries.

- **Place palliative care on the international donors' agenda.** From the standpoint of health care budgeting, palliative care is a wise expenditure, as it shifts resources from more expensive settings and practices to less expensive ones. That said, there is not a single resource-limited country that has sufficient resources to shift. People in low-resource countries are impoverished, health care systems are impoverished, and therefore palliative care is impoverished. It is unrealistic to expect that these countries will be able to sustain their palliative care systems without international aid from governments, international bodies, and nongovernmental organizations and private donors.

A number of collaborative networks now contribute substantially both in advocating for palliative care and coordinating resource allocation from donors to service providers in the under-resourced nations. Aside from the Open Society Foundations, these include the International Association for Hospice and Palliative Care, the National Hospice and Palliative Care Organization, the Foundation for Hospices in Sub-Saharan Africa, the Diana, Princess of

Wales Memorial Fund, Elton John AIDS Foundation, and regional associations.

Still, the global community will need to apply all its ingenuity, moral persuasion, and perseverance to building and financially sustaining these systems. Indeed, among the five recommendations of the IOELC Donor Report is “an awareness-raising campaign to focus attention on worldwide need” for palliative care. Such campaigns can be organized by donors, palliative care organizations and associations, and patients and their advocates.

- **Plan and coordinate for sustained funding.** As awareness of need grows, so will the demand for aid. Already, those regions that have been able to garner more attention have also garnered more funds. The IOELC report found large regional discrepancies in donor activity, with Latin America and mainland China on the short end.

Sustaining funding will require more and better information, which must be better organized and disseminated. The Donor Report recommends a global register of international hospice and palliative care donors and their activities that is more complete than the one it was able to assemble in the first stage. Such information will abet global collaboration and coordination, which in turn can increase leverage and efficiency in giving—all crucial to sustainability. “Greater understanding of the variety of donors and their areas of interest,” the report says, “may lead to a more strategic approach to palliative care development on the part of both funders and grant-seekers, especially in resource poor regions of the world.”

Sustainability also means planning for the long haul. In announcing the United States’ appropriation for PEPFAR

in 2007, President George W. Bush emphasized the need to shift from an emergency plan to a sustainable response. That would also suggest increasing funds, which will be needed as the world’s population ages and people live longer with life-limiting diseases and conditions.

Recommendations

A myriad of opportunities await the international donor community and health care policymakers for advancing palliative care, especially in the resource-limited regions. In broad outline, the following are IPCI’s recommendations for the next steps to take:

- **Nurture leadership.** Supporting early and mid-career leaders in palliative care around the world is a priority for IPCI. The Institute for Palliative Medicine at San Diego Hospice’s new Leadership Development Initiative will enhance professionals’ skills in education, research, clinical care, advocacy, and communication. In turn, these emerging role model professionals can form a global network of skilled palliative care experts. They can work in their own countries, as well as internationally, for the expansion of palliative medicine and the integration of palliative care policies into national and international health systems.
- **Rationalize and proliferate the best clinical education.** Among the greatest challenges facing palliative care, especially in the resource-limited regions, is the dearth of trained health care workers. In the past two decades, leading specialists have passed their expertise on to physicians, nurses, social workers, and others using a

variety of pedagogic models. These have included distance learning programs, seminars and lectures, interactive didactic sessions, and bedside training. Now, evidence is mounting that bedside training is crucial to producing optimal gains in knowledge and competency. The so-called San Diego model—named after the hospice where Frank Ferris developed it—is a three-week course that combines interactive classroom learning with experiential training at the bedsides of ill and dying patients.

The International Palliative Care Initiative is committed to a combination of interactive didactic seminars and experiential learning and recommends that other institutions, national and global associations, and donors join in supporting innovative educational models that can be sustainable around the world. This will not only increase the ranks of palliative care workers but also ensure they are being trained by the most effective and culturally appropriate methods.

- **Support the World Health Organization in developing and refining pain and policy guidelines.** Throughout the world, policymakers, health care professionals, and citizens continue to still fear that opioid analgesics are harmful. The fear of addiction is a major reason that pain-control medicines are not available or not being prescribed to eight of every 10 patients who need them. Understanding that evidence-based guidelines can assuage such fears and improve pain management, the WHO continues to expand and revise its library of pain policy guidelines, most recently working on revised guidelines for acute pain, for chronic cancer pain and for chronic non-cancer pain.

To answer the long-expressed need for revised pain guidelines for children, the WHO's Access to Essential Medicines Program will release Guidelines for Pediatric

Pain in 2010. A 2008 IPCI grant supports the guide's development, publication, and dissemination. While new documents are generated, older ones including the WHO's "Achieving Balance in National Opioid Control Policy: Guidelines for Assessment" and its Essential Medicines for Palliative Care List need periodic review and revision, with changes in laws and political situations and advances in pharmaceutical research and clinical practice.

IPCI encourages national and international organizations and donors to support the WHO in these efforts by funding these initiatives, helping to translate and disseminate them once produced, and educating professionals and the public about these guidelines and their effective use.

- **Develop Resource Centers.** Leadership, clinical training, and policy development cannot happen without institutions that foster them. Such exemplary and standard-bearing institutions can be research centers, such as the International Observatory on End of Life Care in Lancaster, England, or King's College Palliative Care Institute; hospices and hospital departments like Hospice Casa Sperantei in Brasov, Romania; and policy institutes such as the University of Wisconsin Pain & Policy Studies Groups or the Catalan Institute of Oncology. Many fulfill several functions at once. The WHO is identifying Coordinating Centers in palliative care worldwide, and national and regional departments of health and regional and national associations are doing the same in designating Centers of Excellence.

Aside from endeavoring to merit such status themselves, members of the global palliative care community can buttress these centers with financial and technical assistance. They can also help enable advocates and

clinicians to convene at these institutions, travel to them for training, or invite their faculty to visit—in other words, to encourage and partake of what they are meant to be: incubators of regional and global palliative care development and integration.

- **Encourage a strong civil society voice, especially among patient advocates.** Educating the public about the right to pain relief and palliative care is essential. Patients and patient support groups for the elderly, the disabled, and children—along with family members and activists—need to demand relief from pain and access to effective treatments to improve quality of life. Such groups need to put palliative care and pain relief on their advocacy agendas and work to reform government policies that prevent them from receiving quality care at the most vulnerable time of their lives. They need to monitor their governments' health budgets to be assured that appropriated funds are spent for accessible services.

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The need for palliative care is great and growing. Fifty-eight million people die annually—45 million in developing countries. Of these it is estimated that at least 60 percent, or 35 million, will have a prolonged advanced illness before dying and would benefit from palliative care. In the developing world, where preventive medicine and good medical care are scarce, two illnesses account for the lion's share of pain and mortality among both adults and children: cancer and AIDS. Usually diagnosed too late for meaningful curative treatment, palliative care is the humane, affordable answer.

For the past decade, advancing palliative care globally has been the major goal of the Open Society Foundations International Palliative Care Initiative. This report offers a snapshot of the challenges and opportunities for advancing palliative care globally. It aims to inspire potential partners, donors, and advocates by sharing a few stories of some of the amazing individuals and organizations working to relieve the suffering of millions of people worldwide.