About the Institute

History
In 2003, the schools of the health sciences at the University of Pittsburgh, in collaboration with Family Hospice and Palliative Care, established the Institute to Enhance Palliative Care. These scholars and health professionals from diverse fields have joined together to improve care for people who are seriously ill or dying in Western Pennsylvania. This unique collaboration of an academic research institution and a community-based hospice and palliative care provider makes it possible to gain understanding of a greater range of people’s experiences facing serious illness.

Mission
The mission of the institute is to improve the access to and quality of palliative care in Western Pennsylvania by (1) educating healthcare providers regarding palliative care, (2) conducting research into the best ways to provide palliative care, (3) raising public awareness about the availability of palliative care, and (4) advancing public policies that support excellent care for people who are seriously ill.

The goal of palliative care is to maximize quality of life for patients living with a serious or life-threatening illness.
What is Palliative Care?

How does this approach work to maintain quality of life for those who are living with and dying from serious illnesses?

“A patient can benefit from palliative care at any stage of serious or chronic illness, from the time the disease is diagnosed to its final stages. It takes an entire team, including a doctor, nurse, pharmacist, psychologist, social worker, and chaplain, to provide palliative care. One important aspect of care is controlling the patient’s bothersome physical symptoms, such as pain, shortness of breath, nausea, and fatigue. Careful use of medications often achieves this goal. Another aspect is helping the patient and his or her family plan for the future and establish goals for medical care.”
Why does palliative care need to be “enhanced”?

Although caring for and comforting those who are sick and suffering is an impulse as old as humanity, the professional approach known as palliative care is relatively new. It has developed over the past 30 years in response to the changes wrought by modern medical advances on how people experience illness, dying, and death. Before the 1900s most people died quickly from acute infectious diseases or accidents. Now, drugs, machines, and procedures are often able to keep people alive for a longer time with conditions such as cancer and end-stage heart, liver, kidney, and lung diseases. As a result, most people in the United States die from long-term chronic illnesses, which involve a prolonged period of progressive loss of function and numerous distressing symptoms. Palliative care works to alleviate these symptoms and maintain the best possible quality of life for such people and their families.

Public opinion polls, medical organizations, and research institutes have clearly documented that large numbers of seriously ill and dying patients and their families suffer needlessly due to gaps in the healthcare system. These problems are especially persistent in Pennsylvania, which has one of the highest proportions of elderly in the United States. People who die in Pittsburgh are more likely than many others across the rest of the country to experience hospitalization in the last six months of life and are at higher risk for a hospitalization that includes admission to an intensive care unit. While some of these hospitalizations lead to meaningful recoveries or welcome improvements in health or quality of life, all too often patients bear physical, emotional, and financial burdens of unhelpful and unwanted medical care near the end of their lives. We urgently need new approaches to care for seriously ill patients that promote comfort, dignity, continuity of care, communication, and family support.

Research shows that seriously ill patients and their families want and need what palliative care offers: relief from symptom distress, control over what happens to them, avoidance of prolongation of the dying process, help with the burden on family caregivers, and the opportunity to strengthen important relationships. And yet:

- Studies have shown that 40 to 50 percent of nursing home residents in the United States live in persistent pain, and 50 percent of hospitalized dying people have moderate to severe pain more than half the time before they die.
- Although Gallup polls consistently show that 80 to 90 percent of us would prefer to die at home, the vast majority die in institutions, many receiving unwanted, burdensome care.
- For patients who die at home, the financial, physical, and emotional burdens of caregiving fall heavily on isolated nuclear families and predominantly on women.

People with serious illnesses and their families are suffering in a world where we have the resources to prevent it. Why? Palliative care is appropriate throughout the course of a serious illness. Because there is a misperception that this type of care is only useful at the end of life, the honest, open communication between doctor and patient, so necessary for realistic planning in the face of a grave prognosis, often fails to occur. Moreover, many patients and families are unaware that experts in palliative care could help their physicians alleviate the pain, stress, and other symptoms of critical illness. This is one of the reasons that palliative care reaches only a small fraction of those who could benefit from it. In addition, relatively few health professionals have been exposed to the knowledge and skills required for excellent palliative care. Most physicians are trained to cure disease rather than promote patients’ highest possible quality of life in the face of serious illness. According to the Institute of Medicine and a report by the National Cancer Policy Board, in order for palliative care to fulfill its promise, our society must make significant progress on three fronts: research, professional education, and community engagement and education. These are the three areas of focus of the Institute to Enhance Palliative Care.
The Institute’s Focus

1. Research
2. Education and Training
3. Community Education and Advocacy

I. Research

Research into the most effective treatments for physical, psychosocial, and spiritual suffering: Precisely because it is a relatively young discipline, palliative care is only now beginning to develop the solid evidence base, research capacity, and standards of excellence through which all other medical disciplines have sustained themselves and gained credibility and acceptance. Until the very recent past, palliative care has been overlooked in the competition for research funding from the National Institutes of Health (NIH), which is the largest source of healthcare research funding in the United States. A review of late 1990s funding found that NIH’s National Cancer Institute spent less than 1 percent of its budget on activities related to palliative care.

During the past decade, however, talented researchers in medicine, nursing, the social sciences, and humanities have begun to recognize the importance of palliative care. Research is fundamental to eliminating unnecessary suffering during critical illness and at the end of life. The Institute to Enhance Palliative Care focuses the research capabilities of the University of Pittsburgh on palliative care with a particular emphasis on educational techniques, communication regarding end-of-life issues, clinical trials in palliative medicine, and family and caregiver needs. The institute’s partnership with Family Hospice and Palliative Care widens the research horizon beyond the University to a much broader, community-based population. Institute-affiliated researchers are pursuing innovative, rigorous research; mobilizing the resources of the University’s schools of medicine, nursing, and public health; and making special efforts to reach subgroups of the population that have been underrepresented up to now in research of this kind.

Current Research Programs and Initiatives

Palliative Care Pilot Research Program:
This institute-funded grant program is designed to provide the necessary research support for preliminary work that leads to external funding, addressing an important issue in palliative care that is likely to lead to future substantive work in the field.

- **2007–08 Award:** End of Life Surveillance: Test and Incorporation of End of Life Module in 2008 Allegheny County Behavioral Risk Factor Surveillance Survey. S. Albert
- **2006–07 Award:** A Pilot Study of Emergency Physician, Hospitalist, and Intensivist Communication Strategies and Decision Making for Critically Ill Elders with End-Stage Cancer. A. Barnato
- **2005–06 Award:** Examining Renal Provider Understanding of Chronic Hemodialysis Patients’ Symptoms: A Pilot Study. S. Weisbord

Institute-Affiliated Research: Examples of projects are listed below by title, researcher, and funding source. More information is available on the institute’s website at www.dgim.pitt.edu/iepc/research_new.htm.

Clinical
- Collaborative multi-site study on the Impact of Palliative Care Consults on Outcomes for Hospitalized Patients with Advanced Cancer. M.B. Happ, R. Arnold National Cancer Institute through the National Palliative Care Research Center

Educational
- Critical Care Communication: Teaching Intensivists Communication Skills. R. Arnold, National Palliative Care Research Center, Jewish Healthcare Foundation
- End-of-Life Education in the Third Year of Medical School. D. Barnard, National Cancer Institute

Health Services
- Hospital-Level Variation in Treatment Intensity. A. Barnato, National Institute on Aging
- Improving Quality of Life of Nursing Home Residents. H. Degenholtz, The Commonwealth Fund
The Institute’s Focus

“Nothing I have learned this year in the basic sciences will leave an impression on me as this course has. … I feel that I have a framework now with which to approach the issues of terminal disease, the dying patient, the surviving family members, palliation, and bereavement.” First-Year Medical Student

II. Education of Health Professionals

Education of Health Professionals in State-of-the-Art Pain and Symptom Management, Communication, and Other Palliative Care Skills: Education in palliative and end-of-life care is often tangential to curricula in medical, nursing, and other health sciences schools, leaving many medical professionals unprepared to meet the needs of patients with life-limiting illness and those at the end of life. For the past several decades, curriculum time, faculty prestige, and research money have flowed largely toward cure-oriented science and technology and hospital-based care, neglecting the needs of incurable and dying patients and their families. At both the medical school and residency levels, data consistently reveal that these programs inadequately prepare students and residents to: 1) discuss end-of-life decisions with patients and families, 2) manage pain and many other common symptoms near the end of life, and 3) address psychological and spiritual issues related to death and dying.

As a national leader in curriculum innovation in medical education for palliative care, the institute works with a variety of departments, schools, and centers at the University of Pittsburgh to enhance and improve the education of providers across disciplines and at all levels of training. The institute mentors and encourages students in nursing, medicine, social work, and pharmacy to participate in research, clinical, and educational programs, as well as to choose careers in palliative medicine.

Current Education Programs and Initiatives

Medical School Education and Curriculum Development:

First Year: Learning from Patients with Life-Threatening Illness is an elective course that gives first-year medical students the opportunity to learn directly from patients and families what it is like to deal with life-threatening illness.

Third Year: Under the leadership of David Barnard, the institute’s director, palliative medicine faculty are utilizing web-based educational technologies to deliver “just-in-time” palliative care learning materials at the bedside to medical students in all required clinical rotations. This is possible with a four-year grant from the National Cancer Institute.

Fourth Year: An elective in palliative medicine offers a structured four-week clinical rotation under supervision of palliative care staff to increase students’ awareness, knowledge, and clinical skills when dealing with terminally ill patients and their families.

Postgraduate Medical Education Residency: In addition to providing an annual lecture series on core palliative care topics for residents, palliative medicine faculty spend varying lengths of time supervising residents in clinical training on the palliative care service seeing patients and developing treatment plans.

Fellowship

- Senator H. John Heinz III Fellowship in Palliative Medicine: This two-year fellowship, generously funded by The Heinz Endowments, prepares fellows for an academic career in the growing field of palliative medicine with a focus on clinical research.

- Lecture Series: Critical care medicine and Hematology-oncology fellows attend lectures in palliative care with the option of spending additional time rounding on the palliative care service. Geriatric fellows also participate in a two- or four-week block in palliative care as part of their clinical training.

- OncoTalk: Enhancing Patient-Oncologist Communication. Intensive communication skills training retreats for medical oncology fellows through University of Washington Seattle http://depts.washington.edu/oncotalk/

Social Work Education

- Evelyn Amdur Palliative Care Social Work Fellowship: Social workers—with their expertise in the psychological and social aspects of illness, family dynamics, and community resources—are critical members of the palliative care team. This fellowship provides an intensive one-month internship in palliative care social work under the guidance of one of the nation’s leading academic palliative care programs.
Community engagement and education to raise people’s awareness about their options for high-quality palliative care so they can demand it for themselves and their loved ones: Most people’s needs and desires in the face of very serious illness can be summed up in three words: comfort, companionship, and control. Comfort means that pain and other troublesome physical or psychological symptoms are managed with skill and compassion. Companionship means that critically ill and dying people and their families are never abandoned by their caregivers or forced to bear their suffering silently or alone; rather, the last phase of life should be a time for strengthening relationships and finding meaning. Control means that one’s choices for treatments and settings for receiving care are respected and that choices are based on open, honest, and clear communication between providers and patients throughout the course of the patient’s illness.

Unfortunately, we are still far from the day when these needs and desires are consistently met in our healthcare system because of the system’s orientation toward cure at any cost and our contemporary culture’s removal from and subsequent discomfort with the reality of dying and death. Too often, seriously ill patients suffer from inadequate pain and symptom control, lack of communication about their illness and options for treatment, and poor psychosocial and spiritual support. The time has come for a transformation in care for those with serious illness and at the end of life. Because so many patients and families who receive palliative care tell us they wished they had known about these services sooner, the institute is playing a leading role in outreach to the public with information about palliative care and in mobilizing broad public demand to improve services for the seriously ill and dying across the continuum of care in all communities.

“I will never forget our class. It is, hands down, the most important thing I have done in two years.”

Participant in Introduction to Compassionate Care for the Dying course
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