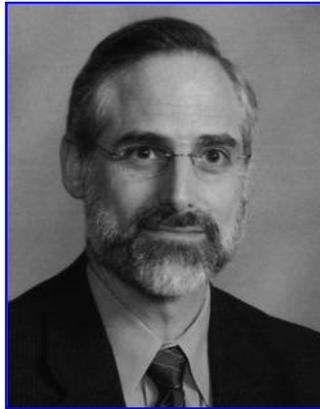


Palliative Medicine: From Paradigm to Best Practice



Russell K. Portenoy, M.D.

Love and work are the cornerstones of our humanness.

Sigmund Freud

From Pain to Palliative Medicine

PALLIATIVE CARE ATTRACTS PHYSICIANS from diverse backgrounds and interests. My interest began with pain management. During my residency in neurology at the Albert Einstein College of Medicine, I was fortunate to meet Dr. Ronald Kanner, who was Dr. Kathleen Foley's first Fellow at Memorial Sloan-Kettering Cancer Center and had recently joined the neurology faculty to work in pain management. When he told me during our first meeting that he was a pain specialist, I asked him whether he was sure. Pain is a symptom and not a disease, I believed, and I assumed that Dr. Kanner was joking. I then followed him on rounds. I saw that there was nothing funny about pain and that physicians who could bring comfort to the suffering had a high calling and a fascinating job. After a fellowship with Dr. Foley and a brief stint on the faculty of Albert Einstein College Of Medicine, I joined the Pain Service at Memorial Sloan-Kettering Cancer Center in 1987, first as the Director of Analgesic Studies and then as Co-Chief of the service.

We were initially cancer pain specialists, but the late 1980s yielded insights that profoundly altered our perspective. With nudging from European colleagues, we came to realize that the narrow focus on pain in a population with life-threatening illness was inadequate, and was truly best viewed as a wedge into the broader and more complex array of problems associated with serious illness. The unsettling sense that a deep knowledge of a symptom still left a

profound ignorance of the patient brought me and my ilk (pain specialists with interest in the medically ill) into the fold of palliative medicine.

My interest in palliative medicine highlighted the uncomfortable reality that years of training had left me woefully ignorant about the key concepts and skills that are foundational to palliative care. I also needed to learn how to manage refractory symptoms other than pain; how to address the psychosocial and spiritual impact of advanced illness (particularly noncancer illnesses, and particularly among minority cultures); how to communicate well about devastating illness, and support goal setting and shared decision making; how to do bedside ethical analysis; how to manage caregiver burden and bereavement; how to address the medical and other needs of the imminently dying (particularly at home); and how systems like hospice, home care and nursing homes work.

Oddly, it was easier to study and be mentored into greater competence in an array of challenging clinical domains than it was to create an intellectual framework on which I could hang my skills and my interests in program development and research. Like the discipline overall, I struggled with the definition of palliative care even as I did its work.

What's In a Name?

It was difficult to self-identify as a subspecialist in palliative medicine when there was no definition of this field that

was uniformly meaningful to those who were attracted to it. I tried to understand the philosophical, logistical, and pragmatic differences in the clinical and academic work lives of colleagues, all of whom were clearly committed to improving the lot of people with serious and advanced illnesses. How was palliative care related to end-of-life care, hospice care, disease management, “just good medical practice?” When trying to become proficient in a new subspecialty, it is distracting to hear colleagues promote different models, squabble over focus or definition, or worst of all, express a level of apathy or ignorance that could leave a less driven person wondering about the point of it all.

Tipping Points

The past 15 years have witnessed a series of tipping points that have been personally meaningful and have yielded a gravitational pull to a common understanding, which in turn, has driven a momentum to change. We—colleagues in different disciplines who work in different health care systems, in diverse settings, and with varied populations—have coalesced around a definition of palliative care as an interdisciplinary therapeutic model appropriate for all types of patients with serious or life-threatening illness. This model is appropriate throughout the course of illness and is guided by core precepts, including a focus on patient and family; support for patient autonomy and respect for culture and individual differences; shared clinical decision-making based on empathic communication about the goals of care; coordination in care planning; and expertise in the management of suffering related to biomedical, psychosocial, and spiritual factors.

This definition bridged many divides: Palliative care should be part of best practice in numerous disciplines, but the interdisciplinary clinical expertise required to manage highly complex sources of distress justified a subspecialty in its own right. Hospice programs can provide specialist-level palliative care when death is predictably near; specialist care “upstream” from hospice could be provided through institution-based consult services and other models, all of which strive for a standard of care that includes a team with special competencies in multidimensional assessment, communication and goal setting, symptom control, end-of-life care, and other domains.

This paradigm rationalized the direction of my career and gave meaning to my evolving volunteer life. It also has been the foundation for simply amazing changes on the national scene.

Volunteer and Work Lives

As a volunteer, I have been privileged by a decade of work with a small group of extraordinary people, who together created the infrastructure for a U.S. physician specialty in palliative medicine. How extraordinary to see this effort effloresce into “Hospice and Palliative Medicine,” a formal subspecialty of 11 primary boards of the American Board of Medical Specialties, with training programs accepted by the Accreditation Council on Graduate Medical Education and

potentially funded by the federal government. I also have had the ongoing pleasure to contribute to the incredible expansion of the American Academy of Hospice and Palliative Medicine, and to work with many others on committees and task forces supporting the creation and dissemination of consensus statements, education programs, and research initiatives for palliative care.

The paradigm gave me the talking points I needed to mold my work life. In 1997, I was given the unprecedented opportunity to found the Department of Pain Medicine and Palliative Care (DPMPC) at Beth Israel Medical Center in New York, the country’s first such department in an academic center. The Department celebrated its tenth anniversary with an interdisciplinary full-time faculty in both palliative care and pain management; a clinical program that includes a consult team, an ambulatory practice, an inpatient unit and an extraordinarily close relationship with a large hospice program (Continuum Hospice Care); and an academic program that supports training for physicians, nurses and social workers, and many educational and research initiatives. The DPMPC is home for the *Journal of Pain and Symptom Management*, which in its twenty-first year is sponsored by both the U.S. Cancer Pain Relief Committee and the National Hospice and Palliative Care Organization, and supports the dissemination of research findings and best practices in hospice and palliative care.

There have been truly extraordinary changes since I finished my formal medical training and began my real education. Most of those who have been part of this have been toiling in hospitals or hospices, representing an emerging discipline and showing its value family by family. I feel proud and not a little awed by it. I also am aware of the threats to further progress: continued marginalization of palliative care within organized medicine; a very sick health care system unlikely to shift significant dollars without a fight; the needs within the discipline for further elaboration of the competencies that define specialist care; the challenge of building a workforce of specialists; the profound need to embrace research and identify funding so that there is a growing evidence base for at least the medical interventions in palliative care; and many other issues. It will take much more time and the efforts of many to mainstream palliative care and make it sustainable through integrated clinical and academic systems.

Fortunately, people need competent palliative care and we are on the right side in pushing for success. Also, those of us who embrace this discipline tend to communicate well and believe in the power of teamwork. I have every confidence that we will succeed.

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