

## Building the Field of Cancer Pain

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I also realize that not every patient can be saved but his illness may be eased by the way the doctor responds to him and in responding to him the doctor may save himself. But first, he must become a student again. He has to dissect the cadaver of his professional persona. He must see that his silence and neutrality are unnatural. It may be necessary to give up some of his authority in exchange for his humanity. In learning to talk to his patients, the doctor may talk himself back into loving his work. He has little to lose and everything to gain by letting the sick man into his heart.

—Anatole Broyard in *Intoxicated by My Illness*

**W**HEN YOU ARE ASKED to write for the *Journal's* Pioneer Series it is hard to communicate the lack of planning in one's career as it has evolved. I was neither first in the cancer pain field nor a pioneer but one of those lucky individuals who stumbled into caring for cancer patient's pain based on a mentor's useful advice. Having had the great fortune to work with smart, engaged, enthusiastic teams of people, I learned how we all considered ourselves pioneers in each of our own programs and silos. In retrospect, my career looks organized, stepwise, focused, and at times, even visionary. In reality, it was opportunistic, chaotic, challenging, and difficult. For each new task that I took on, I had to go to the bottom rung and climb the ladder of experience often making mistakes that might have been avoided with greater attention to detail or less certainty on my part. Along the way, my greatest teachers have been the patients and families for whom I have cared for who were generous and active participants in our clinical studies as we learned from them and with them.

### EARLY BEGINNINGS

After my internship in medicine and neurology residency at the New York Hospital, I was appointed as a Special Fellow in neuro-oncology at Memorial Sloan Kettering Cancer Center (MSKCC) and assigned the task of developing a clinical pain research program in collaboration with Dr. Raymond Houde and colleagues, Ada Rogers, Stanley Wallenstein, and Charles Inturrisi. Dr. Jerome Posner, the founder of the field of neuro-oncology and then-Chair of the Department of Neurology at MSKCC, had identified pain as a neurologic complication of cancer and was committed to developing a clinical research program. He, with Dr. Houde, had obtained funds from the National Institutes of Health under a rehabilitation grant to support a clinician to address the cancer pain problem.

When I was interviewed for the position, I explained that I knew nothing about cancer and had only a limited experience in seeing patients with neurologic complications of cancer during my residency. Dr. Posner

assured me that I was in good company and that no one else knew much about cancer pain.

The best pain reference text at the time was Bonica's *Textbook on Pain* published in 1953. The textbook devoted some attention to the cancer pain problem but its focus was predominantly on the use of anesthetic approaches and it discouraged the use of oral opioid analgesic drugs except for acute pain.

My own clinical experience except with pain patients during my internship and residency was almost nonexistent. I rarely if ever wrote prescriptions for opioids although I had learned about the clinical pharmacology of opioids at Cornell from Drs. Houde, and Beaver both recognized experts in clinical analgesic pharmacology and part of the Analgesic Studies Group at MSKCC.

### STARTING AT MSKCC

My first task at MSKCC was to try to understand and to better define the clinical syndromes patients exhibited and develop strategies for their management. Much of my own clinical research developed from the experience of seeing patients with painful neurological complications ranging from tumor infiltration of the brachial plexus to epidural spinal cord compression to a wide range of unique cases with base of skull metastases and cranial nerve involvement. The patients had extraordinary neurologic signs and symptoms and provided the unique opportunity to see first hand how pain affected their lives often preventing them from receiving adequate cancer treatment because they could not endure the treatment and forcing them to wish to die rather than endure severe pain.

### LIMITED RESOURCES

It is useful to note that when I began my career in cancer pain there were no really sophisticated radiologic approaches to assess patients. The subtle changes of tumor infiltration could not be readily seen on patients' plain x-rays or bone or brain scans. We did not have available magnetic resonance imaging (MRI) and positron emission scanning (PET) and computed tomography (CT) was just being developed as a diagnostic tool. Similarly, we did not have tumor markers. These limitations in our diagnostic tools impacted our evaluation of patients with pain who were often thought to have psychological rather than physical causes for their pain. One of my patients when he was finally diagnosed with metastatic disease as the etiol-

ogy for the pain symptomatology expressed his relief that there was a real cause for his pain and it was not psychological, because he had even begun to doubt himself. This is a sad commentary on the struggles that patients with pain endured in seeking diagnosis and treatment.

The sad reality was that in 1974, when I began my career, the treatment of pain for most patients with cancer was limited to either nothing, occasional anesthetic blocks, or parenteral opioids, commonly morphine, given on an as-needed basis. I had witnessed this first hand as my own mother had died of cancer in the 1950s and she had suffered from intractable pain in the last weeks of her life. She was grudgingly treated by her general practitioner with parenteral morphine on his rare home visits.

### INTERNATIONAL PAIN AND PALLIATIVE CARE

My introduction to international cancer pain initiatives occurred early on in 1978 when Dr. Bonica asked me to present a paper at a satellite symposium on cancer pain at the First International Association for the Study of Pain Congress in Florence. He wanted me to present data on the prevalence of pain in a cancer center. It was this early study that provided one of the first prevalence studies identifying that one third of cancer patients in active therapy and two thirds of patients with advanced disease had significant pain. Although these data represented a hospitalized patient population in a cancer center, the data have been replicated in both inpatient and outpatient settings treating patients with cancer around the world.

At this meeting, I had the opportunity to meet with Dr. Robert Twycross, a principal researcher at St. Christopher's Hospice and with Dr. Jan Stjernswärd, the Head of the World Health Organization Cancer Unit, and with Professor Vittorio Ventafridda, the director of the Pain Program at the National Cancer Institute in Milan, Italy. This was a particularly fortuitous meeting that led to a life-long collaboration with these three extraordinary individuals in advancing cancer pain management globally through our efforts to make pain and palliative care a public health issue.

### CREATING A PAIN RESEARCH PROGRAM

By 1981, at MSKCC, we had established a separate Pain Service within the Department of Neurology and

had developed a clinical research and educational program with an inpatient consultation service and outpatient clinics. We were designated as a Collaborating Center for the World Health Organization in Cancer Pain Research and Education and became a focal point for international observers to learn how to develop clinical pain programs.

Based on the needs of our outpatients who were receiving active therapy and who had major symptom management problems at the end of life, we created a Supportive Care Program directed by Dr. Nessa Coyle. This nurse-centered 24-hour on-call program provided expert advice to patients and families at home with complicated pain and symptom management problems and is an early example of the simultaneous care model providing expertise in pain and palliative care. This program was particularly necessary because 80% of the patients whom we followed died on active therapy and therefore were not candidates for hospice care.

We developed fellowship programs for both physicians and nurses and had the opportunity to train many of the current leaders in pain and palliative care. For example, Dr. Russell Portenoy, who had been a fellow in our program, returned to Memorial after a short stint at the Albert Einstein College of Medicine, becoming the Director of Research Programs.

### OUR RESEARCH FOCUS

Our research focus was on establishing a scientific basis for the use of opioids. Much of our early work attempted to dispel some of the myths related to opioid use. For example, we studied the use of the Brompton Cocktail and demonstrated that it was the morphine in the analgesic mixture not the cocaine, phenothiazine, or other ingredients that played a role in its analgesic efficacy. We were directly involved in the heroin debate after our randomized controlled trial that demonstrated comparable analgesia with heroin and morphine. This study demonstrated that patients could not distinguish between morphine and heroin except for the more rapid onset of heroin. We observed that oral heroin was an expensive way of delivering oral morphine and argued strongly for the wide availability of oral morphine for patients with pain. Dr. Charles Inturrisi our collaborator from the Department of Pharmacology at Cornell played a major role in the development of our clinical pharmacologic studies that looked at both the pharmacokinetics and pharmacodynamics of analgesics. This work was funded by the National Cancer Institute for more than 18 years with generous funding from the American Cancer Society

and with varying philanthropic support often from the families of patients whose pain we had managed.

When Gav Pasternak joined our group, his laboratory focused on the molecular biology of opioid receptors and more recently on the genetic factor contributing to individual responses to opioid drugs. Again, early on, our group took the lead in postulating the role of opioids in the treatment of patients with various types of pain and we were the first to argue strongly for the role of opioids in neuropathic pain. Based on both our research and our clinical experience, we formulated the concept of a continuum of opioid responsiveness in which some patients required higher doses of opioids and neuropathic pain management was partially responsive to opioid drugs.

Creating and developing the program at MSKCC was an extraordinary experience for me. We used the natural experiment of treating thousands of cancer patients with pain to dispel the myths of opioid use and their potential to alleviate suffering. We learned from our pain patients that addiction was rare, cross-tolerance incomplete, and pain stimuli rather than tolerance alone dictates the needs for increasing opioid doses.

From our early beginnings, it was very clear that although pain was the major symptom for which we were asked to see patients, there was an enormous need for a broad holistic approach to the care of such patients. We had worked closely with the growing hospice initiatives throughout the country but it was not until 1996 that we adapted the name of our service to become the Pain and Palliative Care Service with Dr. Portenoy initially as its co-director and then director.

All the efforts to develop a Pain and Palliative Program at MSKCC were enriched by the collaboration of our program with Drs. Holland, Breitbart, and Lederberg and the many attendings and fellows in the Department of Psychiatry.

### TEAMWORK

It is difficult to write this narrative about my own efforts since so much of my work efforts at MSKCC were a team effort with Ray Houde, Stan Wallenstein, and Ada Rogers working on the development of analgesic methodology, by Chuck Inturrisi and Gav Pasternak at a basic research level, with Nessa Coyle directing our Supportive Care Program, and Matt Loscalzo and Terry Altiglio leading our social work efforts, with our fellows and nurses carrying out the everyday work of caring for large numbers of patients and completing our clinical studies and the coordina-

tion of our service administration by Mary Callaway and Bridget King.

### EXPANDING MY HORIZONS

In 1994, I had the opportunity to lead a funding initiative entitled the Project on Death in America (PDIA), which focused on advancing palliative care and translating what we know into clinical reality. This project was a unique experience with many challenges but with many successes. Over a 9-year period, we were able to fund over 45 million dollars in grants to advance pain and palliative care programs in the United States focused on transforming the culture of death in the United States.

I currently serve as the Medical Director of the International Palliative Care Initiative, which provides over 2 million dollars in funding internationally to advance the integration of palliative care policy into health care systems in resource-poor countries in Central and Eastern Europe and the former Soviet Union and increasingly more globally. We have been able to integrate our previous grantees and scholars from PDIA into these international efforts and the fruits of PDIA continue to flourish. With this initiative, I have the opportunity to continue my advocacy for a public health approach to integrating pain and palliative care into national health care systems.

### WHAT HAVE I LEARNED

Over the last 30 years the field of cancer pain and palliative care have grown exponentially but continue to face challenges that interfere with their full integration into the care of cancer patients both here in the United States and internationally.

My own experiences have taught me that change is slow and incremental and only occurs with persistence and commitment and to a vision of what could be possible. It is people who make the difference and collaboration and consensus works better than individual efforts and warring factions. Creating first rate quality model programs help to convince the naysayers

who reject new ideas and novel approaches and setting standards in research and care are what can advance the field when political advocacy fails.

So my advice to young faculty is simple. Be true to your vision and have unconditional positive regard for those with whom you work. Hire people better than you and let them lead and learn to delegate. Set high standards and always expect more of people than they think they can give. Be critical of yourself and welcome criticism. Realize on any one day that you can only do what you can do and be kind to yourself and others. And first and last, have a life that gives you energy to do the hard work of caring for sick patients and their families. In all of this, there is no right way but what works for you.

### WHAT I HOPE FOR

Making pain relief and palliative care a reality for patients and families is my overarching hope. Integrating this knowledge of care into the daily practice of clinicians caring for patients could provide a seamless approach to transform their ability to treat pain and suffering. Developing and supporting bright, enthusiastic researchers to create novel approaches to improve the care of patients with serious symptoms should be our goal through centers of excellence in academic medical centers. Although care has improved for many patients, we have a long way to go in facilitating access to all who would benefit from expertise in palliative medicine. We need to spend more time educating the public about our hopes and aspirations for the field and most importantly, what we mean by palliative care and symptom management. In short, there is much to be done, and we need to find as many partners as possible to advance our cause and to speak on behalf of this vulnerable population.

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