

## A Palliative Care Career

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Where there is love of man, there is love of the art of healing.

—Hippocrates, *Precepts*

If we had a keen vision and feeling of all ordinary human life, it would be like hearing the grass grow and the squirrel's heart beat, and we should die of that roar which lies on the other side of silence.

—George Eliot, *Middlemarch*

### BEGINNING MEDICINE

**A**FTER TURNING AWAY from a long-imagined career as an English teacher, I entered the family business (medicine). Medical school and residency were both engaging and plagued with considerable uncertainty about where I was heading and how I fit in with the profession. It was also punctuated by a year as a hippie. I was attracted to international health and social medicine, but particularly enjoyed settings such as ambulatory care and psychiatry, where a personal understanding of patients' lives was valued. Finishing my internal medicine training in 1975, which included a part-time fellowship in psychosomatic medicine, I took a position at Massachusetts General Hospital (MGH). My new job allowed me to continue my interest in the doctor-patient relationship, working with an outstanding role model, John Stoeckle. In addition, I was able to practice primary care medicine in one of the hospital's neighborhood health clinics in a poor underserved community.

Almost by chance, on my first day at this first job, I took over responsibility for two homebound patients, and did my first house calls. I was fascinated by the devotion of the family members: one was a frail, elderly woman who was caring for her demented and sometime violent husband; the other a middle-age bachelor son who had many siblings but was alone caring for his demented mother. I was able to help these caregivers continue their labor, mostly through my simple presence (plus a few technical skills). I also was amazed at how my appreciation of their work and my reassurance that they were doing the right thing for their loved ones helped them better endure and carry on in a very difficult and stressful situation.

Another physician-mentor, Roger Sweet, piqued my interest in the skill set required to manage a death at home, and thus launched my career in hospice and palliative care. A small but steadily growing cohort of patients who died at home fostered my clinical expertise in end-of-life care, provided an intellectual challenge and also opportunity for me to become an institutional leader

and innovator. Being a bit of a loner, this area of practice was appealing to me since I got “to carry the ball.” I was likely to be seen as a bit odd by colleagues and acquaintances but also as someone who was working on interesting and praiseworthy issues.

### THE DOCTOR–PATIENT RELATIONSHIP

Over the next 15 years at MGH, I organized a long-running seminar on the doctor–patient relationship, and enjoyed a rich atmosphere of discovery and learning in relevant biomedical and social sciences, provided by colleagues in Boston and beyond. I also taught interviewing and other clinical skills to medical students, and shared in new courses that allowed us to try teaching in different areas. I later wrote a textbook on the clinical interview.<sup>1</sup>

When a small band of enthusiasts began meeting to start the first hospice program in Massachusetts, they reached out to me as the local physician with an interest in home care and end-of-life care. Thus began a happy experience of trying to develop a hospice program while working with a diverse group of nonphysicians—nurses, volunteers, a lawyer, and a priest. The ups and downs were many, and I acquired an appreciation, not particularly heartening, of the challenges of organizing and funding a nonprofit organization.

I also took a few months off to begin writing one of the first U.S. textbook<sup>2</sup> on hospice care. Ironically, the publisher insisted that I not use the term, “hospice,” in the title, assuring me that the word would turn off most physicians, especially oncologists. The writing was great fun and helped consolidate my knowledge of end-of-life care.

### MARRYING INTO THE BUSINESS

Around then, I met my soon-to-be wife, Susan Block, an internist and psychiatrist who was interested especially in cancer care, and who soon took a part-time job as a hospice director. Thus, I have always had at least one close colleague and collaborator who shared my interests and hopes. I continue to learn from and be supported by her.

### THE TIPPING POINT FOR NATIONAL INVOLVEMENT IN HOSPICE

In 1987, Dr. Josephina Magno, one of the founders of the National Hospice Organization (now evolved into

the National Hospice and Palliative Care Organization) invited me to a small meeting on end-of-life care at a rough-and-tumble YMCA camp in the Rockies. There, the Academy of Hospice Physicians (now evolved into the American Academy of Hospice and Palliative Care) was born, once again providing me with colleagues with similar interests and offering many opportunities to develop new academic and administrative programs. Dr. Susan Block and I had great fun revamping the format of the annual meeting, an experience that helped us with many future teaching projects. I also enjoyed creating a quarterly critical review of the palliative literature for the Academy. At the same time, as a member of the organization’s board and later as President, I found myself in frequent disagreement with other board members and its lone employee, and frustrated by their limited commitment and effectiveness in the work. We often disagreed about a host of educational, cultural, religious, and intellectual matters. Finally, as I was trying to create a rigorous board examination process, I severed my involvement with the Academy. I was deeply disappointed and bitter at that time.

### CHANGING FOCUS

While I continued to teach about end-of-life care, especially about pain management, I was finding limited local opportunities in the mid-1980s to engage with hospice programs. I became absorbed in curricular reform at Harvard—the “New Pathway”—and had the opportunity both to learn more about educational methods and to develop programs for the entire medical school. Integrated in my curriculum development and educational practice were the years of experience with studying and teaching the doctor–patient relationship and end-of-life care. Later, as the excitement about educational reform faded at Harvard and the ambitious curriculum became watered down by conservative forces and practical constraints, I again became involved with starting up a new hospice program, focused on the inner city. Again, the project was exciting and brought me in contact with many new colleagues I could enjoy.

### THE TIPPING POINT FOR A PALLIATIVE CARE PROGRAM

Around 1992, the Soros Foundation’s Project on Death in America began its 3-year fellowship program. My goal by then had become to develop a palliative care program that could impact practice and learning at MGH, modeled on the work of such colleagues as Balfour

Mount in Montreal and Declan Walsh in Cleveland, Ohio. The fellowship application allowed me to formulate my goals and recognize their personal importance for me. Then, being funded in the first cohort of “Faculty Scholars” gave me the courage to take the leap of investing the greater part of my professional life in end-of-life care. I also now had the time to devote to this pursuit. Again, I was responsible for building a program from the ground up, but I also was supported by Soros, a new group of Faculty Scholars from around the country, and by many hospital colleagues who were recognizing the value of my work. Importantly, I came to this project after many years of providing good clinical care to general medical patients and contributing to the teaching missions of the hospital and medical school, so I enjoyed credibility at both MGH and Harvard. While I was entering the unfamiliar world of business plans, committee reports, and budgets, I found many helpers in the hospital, while even the skeptics listened attentively to my carefully formulated arguments about the clinical and cultural importance—Declan Walsh had spoken about the importance of “taking the high moral ground”—and the financial benefits of palliative care.

### THE CONSOLIDATION PHASE

The MGH Palliative Care Service opened 3 years later in 1995 and has grown slowly but steadily. I was fortunate to recruit Connie Dahlin, N.P., from Oregon, having known her from working in the same Boston hospice program 4 years earlier. Joined by a part-time social worker and a chaplain plus an administrative assistant, we committed to 24-hour, 7-day-a-week care, based on the hospice model and on principals of comprehensive primary care general internal medicine. Along the way we found a second physician, Eric Krakauer. Our first fellow, Linda King, created a program for herself, but then the National Cancer Institute supported a growing fellowship program. As we expanded our clinical and educational efforts, some fellows joined our practice, while others went on to help with or start new programs around the country. We committed great energy and time to developing our fellowship, knowing that the field sorely needed leaders, and recognizing the tremendous importance of supporting young clinicians in our emotionally challenging work. Our mission continues with ever increasing zeal as we mentor our fellows and help them acquire strong skills in both biomedical and psychosocial/spiritual arenas.<sup>3</sup> Most importantly we help them strike the elusive but important balance between closeness and distance with patients and families; between the professional and the personal and between the intellect and the heart.

### WORKING THE SYSTEM

We have slowly grown our palliative care consultation program by making a careful case to the hospital about required resources needed for comprehensive end-of-life care. We also demonstrate our effectiveness in caring for patients, sometimes accomplished when physician leadership is sharing a case with us. Additionally, Dr. Susan Block and I and our team have developed a “Palliative Care Role Model Program” that has allowed us to teach key leaders at MGH and Brigham and Women’s Hospital about end-of-life care. This program has currently morphed into the Harvard Medical School Center for Palliative Care’s interdisciplinary faculty development course called “Palliative Care Education and Practice.”<sup>4,5</sup> The mixture between clinical, educational, and program development efforts within the hospital and our outreach to others interested in palliative care has provided a valuable balance in my life, and opportunities for very different forms of work and gratification.

Our marketing of palliative care within the hospital has always been done primarily through providing excellent care for patients and families and by offering skilled support to fellow clinicians. Good care and devotion to the well-being of our patients and families is our consistent message. Every referral is an opportunity for us to learn, to teach our clinical colleagues about state-of-the-art palliative care, and to develop supportive relationships with the hospital staff. We win one referring clinician at a time, and we always try to remember that these clinicians, whether fans, skeptics, or detractors, are dedicated to the best care of their patients. Champions in the hospital, particularly the Chief of Thoracic Oncology, Tom Lynch, who eventually became clinical leader of oncology, convey enthusiasm about our work, which, in turn, leads the more skeptical to give us a chance.

### OUTREACH TO OTHER SERVICES LEADS TO PROGRAMMATIC GROWTH

A research project led by Jennifer Temel on integrating palliative care in the care of patients presenting with advanced thoracic tumors, gave us experience in managing a totally different population than the patients with late-stage cancer who constitute the bulk of inpatient referrals.<sup>6</sup> Soon, with the backing of the oncology service, we developed a busy outpatient practice. Similarly, another research project funded by The Robert Wood Johnson Foundation allowed us to bring together the cultures of palliative care and the intensive care unit (ICU), and we discovered many new ways to practice and improve care in the ICU setting.<sup>7,8</sup> A long-time

collegial but slightly uneasy relationship with the hospital pain service was strengthened as we became widely recognized as highly proficient in managing cancer pain in both the hospital and outpatient setting, based not only on our clinical expertise but our commitment to continuity of comprehensive care.

My job continues to change dramatically. With outstanding, interdisciplinary colleagues in the Palliative Care Service providing the bulk of clinical care, I have focused on program development. I spend much of my time doing some of the least gratifying of activities, such as budgets, grant-writing, committee work, and various details of running a program, and must find my gratification in knowing that these activities are necessary for the success of the program and the development of palliative care. At the same time, I have the opportunity to think more broadly about our work within the hospital and our hospital network, to contribute to national activities that promote better end-of-life care, and to foster the careers of my colleagues in the Service and our trainees. I am gratified regularly by seeing the great work done by my colleagues on the Service, including our outstanding fellowship director and associate chief, Vicki Jackson, and now our more junior team members. Direct patient care and collegiality in the Palliative Care Service continue to offer the most immediate gratification. I continue to be energized by the sense of professional skill I bring to the clinical encounter and by the palpable, beneficial impact that even a brief visit can provide to patients and families.

### LOOKING BACK, WHAT COULD I HAVE DONE DIFFERENTLY?

I wish I had better training in being a leader. Some of the details of budgets, scheduling, or committee work can be learned on the job, but the challenges of such chores as motivating team members, organizing a program, dealing with staffing problems, planning for future growth, understanding the culture and processes that influence organizational success and funding and development efforts, might be better taught through class work or mentoring. I also have devoted so much time to direct patient care and administration that opportunities to read and learn have been tremendously curtailed, while time for writing, an activity that I find refreshing and rewarding, has been scant.

### TODAY AND TOMORROW

Considerable excitement today comes from opportunities to build programs locally, nationally, and interna-

tionally, as well as witnessing and participating in our daily work with patients and families. My hope for the future foremost is to foster the next generation of leaders for our program and others. Meanwhile, I am trying to establish our program on a firmer financial footing through development efforts, to create an inpatient palliative care unit, to expand palliative care services at MGH and across the country, and to extend the clinical reach of palliative care to be consulted earlier for more kinds of patients. For myself, I need more time to reflect and write, and to plan for retirement.

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