

Finding My Place

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Although the world is full of suffering, it is also full of the overcoming of it.

—Helen Keller
Optimism 1903

Influences

ON THE FIRST DAY of my internship, at about 8:00 in the morning, I was paged to the CCU. There a patient who was assigned to my service was undergoing resuscitation after cardiac arrest. Running after my resident, we arrived at the bedside of an 89-year-old man with end-stage congestive heart failure. The bed was surrounded by cardiology fellows, nurses, residents, a ventilator, crash cart, and ECG machinery, and the floor and bed were strewn with paper, ECG strips, discarded tubing. I watched as we shocked the patient repeatedly; tried four times to get a central line in; injected pressors directly into his heart; stuck the femoral artery for blood gases; and carried on chest compressions for over an hour. Finally the cardiology fellow called the code. Leaving the patient naked and covered with tubes, paper, and bloodstained sheets, we left his bedside. The patient's wife was seated outside the unit. We all walked past her, to get back to the work of the first day. I do not know if anyone spoke with her to explain what happened. Certainly no one explained it to me.

This patient's death was the first I witnessed. My colleagues were committed to trying to save his life and we applied every technology at our disposal to achieve this end. There was no sense of uncertainty or ambivalence about what we were

doing. Our motives were simple and clear: prolong life. The primary emotion after the code was one of both discouragement and determination—we had failed to save this life, but next time we would know more, do better, and have more knowledge to help us—next time we will get it right. My own emotions were a confused tangle of feelings of complete inadequacy and guilt—I should have learned to put in central lines as a medical student, I should have known how to conduct CPR, I should have arrived earlier in the morning, I should have come in the day before to get to know my patients. The principle of respect for life, that all life—no matter how diminished by disease or illness—is precious, and that the medical profession's only *raison d'être* was to use all tools available to prolong it—was such a fundamentally held assumption that it was not (at least consciously) questioned throughout all my 9 years of training. This patient died 31 years ago in July 1977. I have been carrying him with me ever since.

Three months later, my grandfather, Frank Meier, died suddenly. I adored my grandpa and learned to love ice cream and gardening and to understand that all people were one, from him. He was a socialist in his youth and instilled firmly held values about service to others in his two sons and three granddaughters. He came to visit me in September of my internship, and during his visit, asked me what it meant that

he was waking up short of breath every night, with symptoms that would pass after he sat up for a while. I listened to his chest. He was in pulmonary edema. It turned out he had stopped taking his diuretics because of all the driving he and my grandmother had been doing. I encouraged him to take his diuretics, got him a urinal from the VA but failed to hustle him into the hospital where he belonged. He died without warning, at home, 3 weeks later. Neither I nor any of our family got to say goodbye to him, to thank him, to tell him how much we loved him. Every old person I see on the street or take care of at work reminds me of him. His memory helps me remember that every sick person and every old person is a fellow human being—who could have been my grandfather.

Mentors

It is these and other human influences that formed me. When I was a resident, one of my cardiology attendings, Dr. Jack McAnulty, taught me how to stop and listen carefully to the patient, to the heart sounds. He taught me to pay attention. Dr. Christine Cassel, now president of the American Board of Internal Medicine, was my fellow when I was a resident and my attending when I was a fellow. We worked together at Mount Sinai for a number of years as well. She taught me that intractable social problems are amenable to determination and leadership and strategy. In my first real job at Mount Sinai in 1983, our chairman Dr. Robert Butler reinforced these lessons. He had exposed the unregulated nursing home industry,¹ and based on his work with older patients described the life review process² that underlies the dignity- and meaning-based therapies used in palliative care today. He started the National Institute on Aging to develop the evidence base necessary to provide quality care for older people, chaired the first freestanding department of geriatrics in the United States, and pushed for policies that brought the new field of geriatrics and gerontology into mainstream medicine. For me, he was the mentor for how to be the citizen physician—a physician concerned with the health of all the public. Through him, I learned that the academic model (get grants, do research, publish) was necessary, but far from sufficient to the goal of assuring access to quality care for all Americans. Dr. Butler had never pushed me to do anything I did not want to as a faculty member, but when I told him in 1994 that I was too busy to apply for the new Project on Death in America (PDIA) Faculty Scholars program,³ he refused to take my no for an answer. Because of his mentorship and encouragement, in mid-career I found my true calling in palliative medicine.

Colleagues

As the lucky recipient of a PDIA Faculty Scholar's Award in 1995, I and colleagues (Sean Morrison, Jane Morris, and Judy Ahronheim) started working on palliative care at Mount Sinai Hospital.⁴ We became part of that first cohort of Faculty Scholars, people like James Tulsky and Charles von Gunten and David Weissman with whom I continue to work and count as friends. I remember sitting around a big table at the first retreat and talking about what had brought us to this work, each story rooted in family experiences and transformed into a professional mission and commitment. The relationships developed with our fellow Faculty Scholars

were key to the development of the field—that these people were working toward the same goals made me feel like I was not crazy after all, and gave us courage and energy to continue despite the barriers each encountered at our home institutions. My dear friend and 25-year colleague, Jane Morris, was the nurse running the geriatrics clinic when I joined the faculty right after my fellowship in 1983. She taught me to always see the patient as a fellow human being in pain and she articulated the role and needs of families in meeting the needs of the chronically and seriously ill, years before this was a recognized and reported phenomenon. My 15-year long working relationship with my colleague, Dr. Sean Morrison, director of the National Palliative Care Research Center⁵ (www.npcrc.org), has been critical to my own development as a researcher and to the generation and publication of the outcomes data central to adoption of palliative care program models nationwide.

The Growth of Palliative Care

With more private sector philanthropy (United Hospital Fund in New York City⁴), Jane and Sean and I were able to begin a palliative care consultation service in 1997. I remember worrying about being able to actually help patients with pain since I had never been taught how to manage pain. I remember worrying that we'd be lucky to have 50 consult requests in our first year, so foreign to our hospital's culture was a palliative philosophy of care. I remember worrying that my medical school and hospital colleagues would think I was doing something "soft" and unimportant. I learned quickly that the pain and symptom management was the (relatively) easy part, and we exceeded 250 consultations in year one. The hard part was addressing the goals of care in a culture that did not admit to any goals other than cure. The real surprise, however, was the explosion of demand for palliative care. The fact of our existence as a clinical service seemed to be the catalyst permitting our colleagues to name the problems—their need to acknowledge the suffering of their patients and families and their recognition of the limits of the cure-focused medical model—a demand that has continued to grow steadily and does not show signs of leveling off, either at our hospital or nationwide.

Center to Advance Palliative Care

In 1999, Chris Cassel and I were approached by Rosemary Gibson from The Robert Wood Johnson Foundation (RWJF), to discuss developing an organization aimed at providing palliative care program technical assistance to U.S. hospitals. Here my real education began. Almost everything I had learned in academic medicine (with the important exception of grant writing) was useless to the aims of the Center to Advance Palliative Care (CAPC).⁶ Housed at the Mount Sinai School of Medicine in New York but existing to push the development of hospital palliative care nationwide, CAPC demanded skills and knowledge that I did not have. Thanks to RWJF, however, I was able to work with consultants who did.

The Business Case

Lynn Spragens, a health care finance expert, developed and articulated the business case for hospital palliative care ser-

vices. Taking the cost-avoidance argument beyond the hypothetical, and creating tools that allowed each hospital to analyze their own data on the cost impact of long-stay, complex patients with advanced disease, Lynn created the engine that has under-girded the rapid growth of hospital palliative care in the United States in recent years. Further proof of her argument was published in an Archives of Internal Medicine paper by Sean Morrison and colleagues⁷ demonstrating significant cost avoidance among palliative care patients as compared to matched controls in eight diverse U.S. hospital markets.

Social Marketing

Sharyn Sutton, our social marketing consultant, taught me a profound and powerful lesson about social change: we are not the audience. Things that seem self-evident and of utmost and obvious importance to me are often not perceived as relevant by other people. If we want hospital CEOs to invest in palliative care services, if we want our colleagues to refer to us, if we want patients and families to demand these services, we have to start with where these audiences are and what they think is most important. This principle of marketing, used to brilliant effect by Madison Avenue advertisers, can be as effectively applied to do good in the not-for-profit world. Hence we were able to develop messages that actually increased the likelihood that patients would get the care they need: for patients and families the benefit of palliative care is relief and help without having to “give up”; for CEOs the benefit is improved capacity and throughput, avoidance of unnecessary costs, and improved quality; and for referring physicians, the benefit of a palliative care consultation is saved time and help providing optimal care to the patient. Sharyn articulated the palliative medicine paradox—that minimizing palliative care’s connection with death and dying will actually increase the chances that patients will attain a good death. The impact of this shift in frame for the palliative care field is obvious—palliative care programs have doubled in numbers in the last 5 years, and confirming Sharyn’s prediction, hospice referrals have increased even faster.

Reframing Palliative Care

CAPC’s attempt to redefine palliative care as care focused on relief of suffering and support for best possible quality of life independent of prognosis led to predictable tensions within America’s hospice and palliative care community. Hospice, by regulatory statute, is care focused on the dying: those with a predictably short prognosis. Many feared that articulating the goals of palliative care independent of death and dying might be “a hospital grab for hospice dollars,” or tantamount to “turning our backs on the dying.” Amber Jones, another key CAPC consultant with a long background in health care administration and hospice leadership, kept communications open between hospice and palliative care leadership and her constructive engagement with the negotiation process is the reason we were able to “get to yes.” The intense process of debate and discussion accompanying the effort to define quality palliative care, led to the National Consensus Project for Quality Palliative Care guidelines⁸ and the subsequent National Quality Forum National Framework and Preferred Practices for Hospice and Palliative Care.⁹ The definitions of palliative care ultimately agreed upon by the

field in these two documents were actually adopted by Center for Medicare and Medicaid Services (CMS) in 2008. In the new Hospice Conditions of Participation palliative care is defined without any reference to end of life, prognosis, or death and dying:

Palliative care means patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information, and choice.

73 FR 32204, June 5, 2008

Medicare Hospice Conditions of Participation—Final Rule

Reframing the definition of palliative care toward the needs of patients and families, and away from payment-based prognostic criteria, is a major impetus toward improving access to palliative and hospice care in this country.

Organizational Collaborations

If palliative care is to emerge from the radical fringe and become a part of the standard of care for the seriously ill, our field will require effective and ongoing engagement with major health care organizations in the United States. My mentor and guide in this process is another crucial CAPC consultant, Dr. James Block. Trained as a pediatrician and former CEO of several large academic medical centers in the United States, Dr. Block helped me to leave the isolated ivory tower of academic medicine and guided my introduction to the world of organized medicine: the Joint Commission, the National Quality Forum, and the American Hospital Association among others. Dr. Block understands how things get done at the national organizational level and his mentorship, professional network, and his ability to open doors have led, for example, to development of a Palliative Care Certificate Program at The Joint Commission, and engagement of the American Cancer Society in palliative care research.

Context is All

At the same time as palliative care and hospice underwent rapid growth, a number of social factors including but not limited to Jack Kevorkian, the “right to die” movement, the aging of the population, the rise in chronic illness, the demonstration of high levels of pain and suffering in America’s best hospitals, and the health care financing crisis, all helped establish palliative care as a logical response to a widespread need and a solution to many of these problems. Thanks to huge investment from private sector philanthropy (most prominently RWJF and the Open Society Institute, but many others as well), a number of initiatives prepared the ground for the change that has occurred. Charles von Gunten, and later Russell Portenoy through the American Board of Hospice and Palliative Medicine, worked for years to achieve subspecialty status for palliative medicine with the American Board of Medical Specialties,^{10,11} achieving this major milestone in 2006. Betty Ferrell, Charles von Gunten, Frank Ferris, and Linda Emanuel created and diffused nursing and physician education nationwide through their RWJ-funded End-of-Life Nursing Education Consortium (ELNEC)^{12,13} and Education on Palliative and End-of-Life Care (EPEC)^{14,15} projects. David Weissman catalyzed U.S. medical education through curricular technical assistance at both medical school

and residency levels.¹⁶ Susan Block and Andrew Billings developed a thriving mid-career training program that has prepared hundreds of health professionals to lead palliative care programs in recent years.^{17,18} Bill Moyers directed *On Our Own Terms: Dying in America*, a four-part PBS series seen by millions of Americans that helped launch national awareness of the issues facing the seriously ill in the United States.¹⁹ CAPC developed technical assistance tools and educational programs, and in collaboration with its Palliative Care Leadership Centers,²⁰ has trained clinicians and administrators from thousands of health care institutions in the basic leadership and business skills necessary to establish and sustain a high-quality palliative care clinical service. The common principle of all of these philanthropically funded initiatives has been the conscious and strategic effort to reduce the opportunity costs for palliative care program development, medical and nursing education, and mid-career professional training, by disseminating tools and technical assistance in a nationwide process.

Principles of Social Change

The growth of palliative care in this country exemplifies the principles of diffusion of innovation. Characteristics of a successful innovation include: its relative advantage (How much better would the change be?); compatibility (Will it fit in here?); simplicity (Is it clear and easy to understand?); trialability (Can we pilot before a major investment?); observability (Are the benefits visible and measurable?); and scalability (Can this innovation expand to meet need on a broad scale?). Don Berwick of the Institute for Healthcare Improvement further suggests a consistent sequential approach involving defined and highly specific goals (in our case, developing hospital palliative care services); acting on the principle that all change is local and personal (investing in leadership development at the individual and institutional level); creation of tools and technical assistance for sustainable infrastructure; and diffusion of the innovation in discrete and achievable steps and stages.²¹

Next Up

Rosemary Gibson, palliative care's project officer from RWJF, has often talked about what is needed to integrate palliative care into the genome of American medicine. When this happens, our field will no longer be critically dependent on private sector philanthropy and will instead be a mandatory and regulated component of quality care wherever persons with advanced and serious illness receive medical care. Policy change is required to accomplish this. If the goal is to assure reliable access to quality palliative care for patients and their families, we will need to have an informed public demanding palliative care services; health professionals will have to be trained to deliver it; researchers and funding are necessary to improve care quality; and hospitals and other health care organizations need a financial structure that supports these clinical services. Palliative care leaders and our organizations will have to focus during coming years on advocacy for the policies that will formalize, sustain, and make permanent the changes we have all been a part of. President Barack Obama is committed to real reform of the health care system and since our patient population comprise the 10% with the most serious and complex illness who account for

over 70% of total health care costs, palliative care is a central part of the solution our nation needs. Truly, there is no better time than the present.

Ironies

That palliative care has grown and thrived squarely in the context of the current fragmented and irrationally financed health care marketplace is instructive. It has done so because it meets a widely acknowledged need, builds on currently acceptable and familiar health care practice models (for example, use of consultation medicine, subspecialization), has a strong business case that justifies investment in a cost-constrained marketplace, developed an evidence base demonstrating its benefits in terms of symptoms, satisfaction, and costs, invested in local leaders and the importance of leadership, and has been able to scale up to meet the need. Despite poor reimbursement and physically and emotionally arduous workdays, palliative care has attracted growing numbers of young and mid-career health professionals because the work restores the fundamental impulses of health care professionals to pride of place—as Francis Peabody put it in 1927²²: “The secret of the care of the patient is caring for the patient.” The palliative care movement has proven that change is possible, even now, and even in the midst of a broken health care system. Despite the fact that this paper is one of a series on palliative care pioneers, it is evident from the foregoing that the accomplishments of the palliative care movement have been and will continue to be a collective effort. I am lucky to have such colleagues and co workers.

Step by step the longest march
Can be won, can be won.

Many stones will form an arch,
Singly none, singly none.

And by union what we will
Can be accomplished still.

Drops of water turn a mill,
Singly none, singly none.²³

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