

My Journey

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At first you did not love enough, and afterwards, you love too much.

—Stephen Spender, *Collected Poems*, 1986

I AM HONORED to be considered a Pioneer in Palliative Care, and while I humbly accept the honor, I believe there are many others more worthy of such notable distinction. Unlike many of my peers, I did not forge my career in a community hospice or in a pure academic environment, but rather at the Department of Veterans Affairs (DVA) Medical Center in Phoenix, Arizona, a Deans Committee institution with residencies and fellowships, but a somewhat geographically distant affiliation with the University of Arizona (the University of Arizona is establishing a new allopathic medical school in Phoenix, with the first class scheduled for the fall of 2007). However, the distance was not necessarily detrimental, and in fact, the miles most likely afforded me the opportunity to develop a new program without the academic and political constraints so often dictated by the medical school-DVA marriage.

A HISTORICAL NARRATIVE

I was raised by my grandmother, and in all probability began my career in hospice and palliative medicine

as a young child secondary to my exposure to a series of untimely deaths:

- My parents;
- My grandfather;
- My girlfriend in sixth grade;
- My best male friend at 14 years of age;
- My grandmother's friend (who I found gurgling in our living room, only to die a few minutes later); and
- Several canine pets.

I seemed to be surrounded and enveloped by death as a child, molding and sculpting my emotional and spiritual self. And if I divorce myself from my childhood and analyze and dissect the trajectory of my life, I think these deaths more than anything else directed me to a career in medicine and the care of the chronically and terminally ill. Also, during my internal medicine residency, I was fortunate enough to have a mentor who valued listening to the patient and family, a rarity "back then" when laboratory and radiographic data were spewed from the mouths of attendings and

residents alike (come to think of it, that still happens!). This mentor believed that patients and their families would provide us with not only the sentinel clues to diagnoses, but also words that would touch our hearts as clinicians and fellow human beings.

After finishing my residency in Alabama, I ended up in Florida for 2 years where I practiced geriatrics and end-of-life care (we did not call it hospice in the small community where I lived, and in fact, the Medicare Hospice Benefit was in its infancy at the time). Then through frustration with private sector medicine, I joined the Department of Veterans Affairs and landed in Murfreesboro, Tennessee, for 7 months, and finally Phoenix, Arizona, in the home care department. After doing home care for approximately 1 year, I was transferred to the nursing home, where I thrived in the milieu of chronically and terminally ill veterans and their families. And as time passed, I realized I had found my calling in hospice and palliative medicine (although the word palliative was not routinely used until 15 or 20 years later). My supervising physician at the time was not a “patient person”—his rounds consisted of reviewing charts and occasionally visiting a patient—but with the support of a wonderful nursing staff and nurse practitioner colleagues, I was gradually allowed to develop and refine the scaffolds of a hospice and palliative care program that today includes a nurse coordinator, a home care advanced disease program, inpatient consults, an inpatient unit, a developing clinic (which was subsequently closed but is now undergoing revival), a palliative medicine fellowship, and liaisons with community hospices.

TIPPING POINTS AND CHALLENGES

The hospice and palliative medicine program did not come without challenges, both programmatic and ethical. As you would expect, programmatic issues were many, including getting buy-in and acceptance of the concept of hospice and palliative care. In the early years of my career, what I did was considered to be on the fringe of traditional medicine, kind of like voodoo, and I continuously battled this distorted image. I did not have resources such as the Center to Advance Palliative Care to encourage me and provide programmatic support, but I did have a handful of fellow hospice physicians across the country to nurture my embryonic agenda. Gerald Holman was one of those physicians; not only was he a leader in this fledgling field, but a wonderful clinician and kind human

being who provided necessary sustenance during a difficult journey. His hospice program at the Amarillo Veterans Affairs Medical Center was a true pioneer among DVA programs, and did nothing but further encourage me to pursue my love of hospice and palliative medicine. And similar to other Pioneers, attending my first Academy of Hospice Physicians meeting (the precursor of the American Academy of Hospice and Palliative Medicine) gave me a “professional home” and fostered my continued development in hospice and palliative medicine. To sit and talk with colleagues that understood my philosophy and practice was energizing and invigorating—I realized I was not alone in the metaphorical “medical forest,” but surrounded by physicians doing exactly what I was doing, struggling like I was, and even more important, making a difference.

But the detractors were everywhere in those early years. With great aplomb, they verbally pillaged my program, but looking back with a subjective objectivity, I can understand their hesitancy to openly embrace this unconventional form of medicine. After all, there were no training programs in hospice or palliative medicine, it was not a recognized specialty or subspecialty (and thus, no board certification), and, up until recently, was the domain of our esteemed nursing colleagues—so they naturally wondered why a physician would want to participate in what they viewed as an unorthodox practice of medicine. Also, what I did was admittedly not scientific, and was primarily based upon empiric, personal and case-based observations; but even worse, I used those ghastly, life-shortening opioids (I’m sorry, but my cynicism surfaces). My attempts to relieve suffering with such strange and non-traditional methods were questioned, and as a result, my “hospice practice” did not garner much support from administration or fellow colleagues. For example, there were accusations of euthanasia with the use of palliative sedation, in spite of ethics and psychiatry consults prior to sedation. And in another instance, I received a formal complaint and peer review secondary to the use of intravenous morphine in a patient who had undergone 15 head and neck surgeries, only to have the cancer recur with a vengeance. The patient was terminal, with significant dyspnea, and I administered 5 mg of morphine on three occasions in an effort to assuage this patient’s refractory suffering. Fortunately, the peer review determined that the use of morphine was appropriate and within the accepted standards of community care.

And it has taken many years for me to experience the final event that has been the most profound and

important tipping point for me in my practice of hospice and palliative medicine: the death on October 17, 2006 of a woman I knew for 30 years and with whom I shared many memories, had two wonderful daughters, and in the end, the person who forced me to experience the opposite side of the palliative care equation as a caregiver and a surviving family member rather than as a physician. Her name was Pamela Rousseau. It is not a side of the equation I would recommend to anyone, but it is one we will all walk sooner or later, irrespective of occupational, socioeconomic or cultural status. Moreover, it is a side that leaves one feeling naked, empty, alone, and in need of understanding, all at a time when physicians convey their condolences and say their final goodbyes. And this is exactly what happened to me and my daughters. After a muddled assembly of who knows who at the bedside when Pamela died (I do remember a chaplain, a social worker, and a nurse, but strangely, do not remember a physician), they suddenly vanished (except for the nurse whom I will never forget). We then spent time alone with Pamela, wandered to the elevators, went down five or six floors, walked to the parking garage, left the medical center, and drove to our hotel. Any professional support we had was gone. What magnified this situation was the fact that we were from out of state (she died in Los Angeles), staying in a hotel, with literally no social or palliative net to catch us after her death in a distant city. This is a glaring flaw of hospital care, and I caution any hospital-based palliative care program to be aware of the sudden, albeit unintentional, abandonment of family members after a death. Although not intentional, such abandonment adds salt to the emotional wound, and can unquestionably contribute to a difficult bereavement. Regrettably, we often dismiss the importance of just being there for the patient and family—sitting and listening—and instead feel a need to know the answers (which we don't) or assume an arrogant perch and babble about some x-ray or blood test. And when we do not know the answers, or find it difficult to ascend that arrogant perch, we run, not literally but figuratively—to escape the suffocation of death and our own inadequacies, leaving the family to suffer alone. These understated and underappreciated humanistic qualities of listening and just being there are what make medicine such an honorable and humane profession. But unfortunately, we often relegate the patient to a puzzle that must be solved, rather than a person with a history, a family, and a fading future—or more simply stated, we seem to think the patient is irrelevant, the disease is not—and this is wrong.¹ And since I

have had time to think about and undergo personal introspection regarding this event, her death has given me a deeper understanding of what our patients' families experience and need during a loved one's death, including the agonizing depths of loss and grief, the need for spiritual and emotional sustenance, and the anticipation and hope of healing in the months and years ahead. And while my grief is still very raw, her death has made me even more committed to the concept of hospice and palliative medicine, and in the end, a better physician.

MY HOPE

As with any emerging specialty or subspecialty, the maturation process is fraught with disputes, confrontations, and compromise, all components of organizational growth. But such hardships and tribulations can be good—they remind us of our history, our sacrifices, our patients, and the value of what we do, and stimulate us to advance the science and art of caring for this vulnerable segment of society. Many physicians now entering our newborn specialty do not know the battles that seasoned physicians and nurses have endured in the birth of palliative medicine. I hope that these younger physicians will appreciate these sacrifices, and maintain the art of hospice and palliative medicine—the empathy, the compassion, the nonmedical, and oftentimes intangible components that make the care of the chronically and terminally ill so special: the bond between one human being and another. But a necessary note of caution in an era of evidence-based medicine, managed care, and increased demands on a finite health care budget: maintaining the art of hospice and palliative medicine will require daily vigilance and constant support by all health care providers involved in chronic and terminal care, including physicians, nurses, nurses aids, social workers, clergy, volunteers, bereavement personnel, psychologists, recreational therapists, and dietitians. And unless we are able to adapt and evolve, to try new ideas and learn from our failures, and seek out new and exciting opportunities,² we will most assuredly become stagnant and fearful of change, and in so doing, fail our patients and their families.

So in closing, I want to again humbly accept this honor, and leave you with a poignant passage that echoes through my mind on a daily basis as I travel the difficult journeys with my patients and their families: it is really not as physicians that we meet the suf-

ferer, but rather as persons that we encounter the presence of others who suffer.³

MY THANKS

I want to thank the many mentors and peers who have encouraged me through the years, and supported me during the difficult and trying times. I also want to thank the Department of Veterans Affairs for allowing me the opportunity to develop professionally and pursue my love of hospice and palliative medicine, and the many many wonderful nurses that have touched my life and enabled me to grow not only as a physician but as a person. And finally, I want to dedicate this honor, and my career, to Pamela, a wonderful woman who died far too young.

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