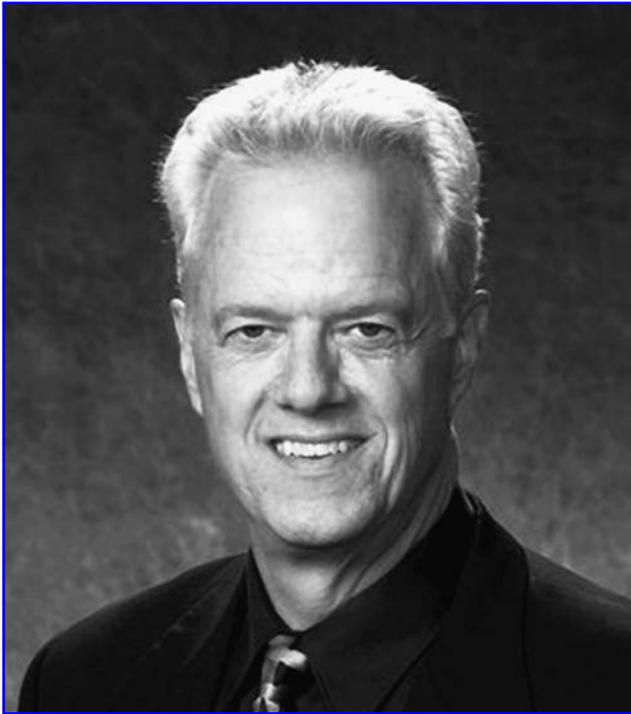


Overpowering or Understanding?

Brad Stuart, M.D.

The way of love is not a subtle argument. The door there is devastation. Birds make great sky-circles of their freedom. How do they learn this? They fall—and falling, they're given wings.

—Rumi



BEING DESIGNATED A PIONEER IN PALLIATIVE CARE is a wonderful surprise. It is a privilege to join this group, but beyond that, an invitation from the community to tell your story is a great gift. I hope what follows is helpful.

Disillusionment and Discovery

My palliative care wake-up call came in 1976, at the beginning of my third year at Stanford Medical School. I had high aspirations for an academic career, possibly in cardiology. For my first clerkship I picked internal medicine.

One of my first patients, Mr. M., had mycosis fungoides, an ugly form of lymphoma that was rare then, although acquired immune deficiency syndrome (AIDS) would make it distressingly common in the 1980s. Fighting end-stage disease, this gentleman had flown a thousand miles for a clinical trial of adriamycin, now a mainstay of cancer treatment.

Mr. M. was near death, confirmed by low blood cell counts and bone marrow effacement. As I worked him up, I wanted to know how he and his wife, a prim woman in a pink wool suit and pillbox hat, were feeling about his condition. Emotions had never come up in class, and I had no idea how to ask about them. My own feelings were mixed. I felt like a coward, and I was ashamed of that. But at the same time I felt a sense of excitement, even awe, looking at this unexplored territory. It reminded me of clear nights as a child, lying on my back gazing up at the empty space between the stars, both scared and strangely calm, trying to imagine how vast that dark immensity could possibly be.

To my surprise (although looking back, I should have known better), not one member of the attending or house staff was willing to admit that Mr. M. might die, probably sooner with treatment than without. I asked the chief resident to call a meeting to discuss this.

The meeting room was packed with eminent academics expecting a typical morning report. I presented the case, and ended with a question: Shouldn't we talk with the patient and his wife about their hopes, their fears, their unrealistic expectations? The room fell silent. This was rare. Normally these people would have been tripping over each other to render an opinion.

"We don't really have a language for this," a professor of hematology finally said. "English might work," I thought, but I was not brave enough to say it. I found myself in a mini-crisis. I had idolized the erudition of my mentors, and the seamless consistency of the body of medical knowledge they espoused. That admiration had buoyed me through many sleepless nights of study. Now in this uneasy silence, I could almost hear the air hissing out of my balloon.

The meeting broke up. Fifteen minutes later the chief resident caught me in the hall. He told me the decision had been made to go ahead with treatment. I volunteered to give it, and mixed the adriamycin myself. I immediately saw why the residents called it "the red death." The syringe, filled with flaming fluorescent scarlet drug, felt like a bolt from Hell in my hand. I infused it slowly into Mr. M.'s intravenous line to avoid local tissue damage, feeling torn because I knew it would ravage what was left of his bone marrow. Sure enough, within 48 hours his platelets dropped to zero, whereupon he bled into his brain and died.

Everyone but me went on to the next case as if nothing had happened.

This willful unawareness of death left me feeling both crazy and curious. How could we devote so much energy to probing the mechanisms of life on the submolecular level, but ignore this massive emotional train wreck right in our midst? [Note to young colleagues: pay attention to those things that make you grit your teeth and clench your fists, for they may contain the seeds of your future passion.]

In case after case I watched clinicians battle vainly against death, without any real consciousness of what dying might actually be about. In particular, I was struck by the almost complete lack of feeling among many (although not all) of my colleagues. Meanwhile, I watched patients and families feel so intensely, so openly, in such a raw and painful way, about their suffering and loss. This disconnect was offensive to me, and my distress was compounded by the fact that nobody else seemed to be bothered by it at all.

Transitions

So I decided to hop off the academic fast track, and plunged into general medical practice in a small northern California community. The glorious system of medical knowledge I had so admired, and still tried to master, now seemed too small. I yearned to find a kind of knowing that was more comprehensive than this. I wanted to learn how to respond openly and honestly to people afflicted with illness and dying, to become truly “response-able.” For a while it felt like a lonely quest.

Then I discovered family meetings. I learned that they could span the emotional gamut from hair-raising to hilarious, but they could also contain pools of silence that felt sacred. There was a lot to learn for all of us, and there always will be. Experience taught me that the real work often started only after all curative treatment options had failed. Then we were free to talk about the unspeakable, and to listen deeply. “Awe” became a measure of the depth we could achieve; “awful” could mean “full of awe.” I learned to navigate through painful emotional waters, to see better in darkness, sometimes, I thought, all the way to the bottom. My own prostate cancer diagnosis and treatment, and caring for each of my parents as they died, also helped me learn to see in the dark.

A New Direction

A stint on our local hospice’s Board of Directors led to a medical director position and a presentation at the annual National Hospice Organization (now National Hospice and Palliative Care Organization) meetings. Then in the mid-1990s, the U.S. Health Care Financing Administration (now the Centers for Medicare and Medicaid Services, or CMS) requested a set of hospice eligibility criteria for patients with noncancer disease. I was privileged to serve as the principal author of the *NHO Guidelines for Prognosis in Selected Non-Cancer Diseases*,¹ pieces of which are still widely used as cues for referral to hospice and palliative services.

Changing the System

The big question for me became and still remains: how can we help people make the transition from living in the world to leaving the world? Despite hospice’s best efforts, a chasm in the United States still separates the treatment of

disease and end-of-life care. In the late 1990s, our group at Sutter Health received a Robert Wood Johnson Foundation grant to fund an interdisciplinary team that provided concurrent treatment and palliative care in patients’ homes. After years of slow progress, the Advanced Illness Management (AIM) program² is just now growing into a system-wide continuum of care linking hospitals, medical groups, and home- and community-based services. We are hopeful that care-coordination programs like AIM could become the glue that helps bind the fragmented pieces of our system together. Meanwhile, a lonely quest has turned into a team effort, with inspired players linking arms to work together around the world. Watching this happen has evoked another kind of awe.

Thoughts on the Future

New opportunities abound in the turbulent world of health care. Heart failure patients, for example, have an overall life expectancy worse than that of most cancers.³ Because the nature and standard treatment of heart failure tend to conceal this fact from patients and clinicians,⁴ a major opportunity exists for programs to combine treatment and palliation, advance care planning and counseling about hospice.

Medicine’s mindset, which mirrors our society’s, has room for growth as well. The dynamics of life involve tension between opposing forces. Living and dying, winning and losing are like the poles of a battery; energy and power come from the tension between them. What frustrates me still is our stubborn insistence on winning and our mindless denial of loss. When things are this one-sided, the healthy interaction of human feelings is missing. There is no generativity and very little healing, even as we strive to cure using fabulously expensive new drugs and devices that yield ever-diminishing returns in mortality reduction. Enrolling patients with cancer in hospice increases life expectancy⁵ as much as treating them in the intensive care unit (ICU), yet ICU care for these patients continues to grow.⁶ As our society ages, as chronic illness becomes more prevalent, and as the working population shrinks relative to the growing number of Medicare beneficiaries, it is hard to imagine how we can sustain the expansion of energy and resource inputs needed to fuel a health care system so oriented toward cure at any cost. On the other hand, as we begin to determine which interventions are helpful and to stop doing what is not helpful, assuming we develop the courage to hold a public discussion about this, palliative care will play an increasingly important role.

Outer and Inner Work

We do not need to change the world. We need to reorganize the way we see the world. It is not that we care about the wrong things. We just do not care enough about the right things. Evidence is good and guidelines are fine; they help us to achieve consensus and to avoid the tyranny of opinion. But I wonder if there is a way for our society to come to a deeper kind of agreement. Overpowering death does not work; understanding does. Death is the limit that frames and defines life. Yes, Americans disdain limits. But, paradoxically, as patients and compassionate clinicians discover together every day, we can find freedom in accepting these limits and working within their boundaries.

The best work is done partly in the world and partly in ourselves. When we go all the way to the edge of life with someone else, if we're truly present and ready to learn, we can look over that edge, into ourselves, into a place where differences finally do rightfully come together, where winning and losing no longer contest each other, where grief and joy are one. When we go down into this well, we may reemerge from the darkness bringing up the water of life. The world needs this now.

References

1. National Hospice Organization. Medical Guidelines Task Force: *Medical Guidelines for Determining Prognosis in Selected Non-Cancer Diseases, Second edition*. Arlington, VA: National Hospice Organization, 1996.
2. Ciemins EL, Stuart B, Gerber R, Newman J, Bauman M: An evaluation of the Advanced Illness Management (AIM) Program: Increasing hospice utilization in the San Francisco Bay Area. *J Palliat Med* 2006;9:1401-1411.
3. Stuart B: Palliative care and hospice in advanced heart failure. *J Palliat Med* 2007;10:210-219.
4. Stuart B: The nature of heart failure as a barrier to the integration of palliative care services. *Curr Opin Support Palliat Care* 2007;1:249-254.
5. Connor SR, Pyenson B, Fitch K, Spence C, Iwasaki K: Comparing hospice and non-hospice patient survival among patients who die within a three-year window. *J Pain Symptom Manage* 2007;33:238-246.
6. Sharma G, Freeman J, Zhang D, Goodwin JS: Trends in end-of-life ICU use among older adults with advanced lung cancer. *Chest* 2008;133:72-78.

Address correspondence to:
 Brad Stuart, M.D.
 Sutter VNA & Hospice
 1900 Powell Street, Suite 300
 Emeryville, CA 94608

E-mail: stuartb@sutterhealth.org

