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Pioneers in Palliative Care

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Cutting Through Yesterday's Understanding

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> The purpose of today's training is to defeat yesterday's understanding.
> —Miyamoto Musashi
> Japanese sword master

James Hallenbeck

I AM HONORED to be included among the recipients of this award, although I find this a bit awkward. I can think of a number of individuals more worthy. In 1993 I accepted a position as a nursing home physician within the VA Palo Alto Health Care System, which included work as the physician for a seven-bed inpatient hospice unit. This unit, established in 1979 was one of the earliest of its kind in the United States. I had no relevant training in geriatrics or hospice care and despite a rather blue-blooded medical education as an internist, I quickly realized I was grossly incompetent. This really scared me. I sought out geriatric and hospice literature and immersed myself in an intense self-education program. Fortunately, the first edition of the *Oxford Textbook of Palliative Medicine* had just been published. It was a godsend. As I came to better understand what was in fact known, I became rather angry. Why had I not been exposed to this important information during medical school or even residency training? I then made two resolutions.

1. First, to create a supportive learning environment for clinicians in hospice and palliative care, and
2. Second, to try to answer—at least for myself—a burning question: Why is it we are doing such a terrible job caring for the dying?

Since then that question has expanded into a broader inquiry as to what has gone wrong, so terribly wrong in health care.

Examining the Question

The nature of my inquiry into the question shifted over the years. Initially, I considered the possibility that the problem might be, as I so often heard, "those damned doctors." Are we in some way congenitally flawed? I do not think so. Most doctors go into medicine for all the right reasons and with good hearts. However, there is something about the culture of medicine that too often scars these hearts. So I examined the question from the perspective of culture and society. While reading heavily about cultural aspects of death and dying, I came across some writing of Arnold Toynbee, the great historian, who in his old age became particularly interested in death and dying.[1] Toynbee criticized social sciences such as anthropology and sociology as being too one-dimensional in their neglect of history. This shook me, as I realized I had made just this mistake in too narrowly focusing on culture. Thus I began to read more on the history of death and dying. Phillip Aries' book, *The Hour of Our Death,* was particularly influential on me.[2] Through my reading it became clear that changes in how we become sick and die had outpaced our culturally conservative ways of dealing with death and dying, creating rather a cultural gap. So, I thought that perhaps through education this gap could be bridged, accelerating necessary changes in how our society and medical culture deals with death and dying.

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Early Friendships

I was very fortunate in my early years to make the acquaintance of David Weissman and Charles von Gunten, who became dear friends. Under David's leadership (1999) I participated in an ambitious program to improve housestaff education in palliative care.[3] That was a wonderful experience. We worked with over 200 residency programs. What was most memorable and rewarding was the opportunity for us faculty to observe each others teaching. We made a point to give each other feedback on what worked and what did not. This experience and my work in developing a faculty development program in end-of-life care at Stanford help me develop a deeper appreciation for the art of teaching and the fact that whatever one's innate talent or lack thereof, dedicated practice combined with ruthless feedback could indeed make one a better teacher.[4]

It's the System, Stupid!

The SUPPORT study of 1995 was a wake-up call.[5] SUPPORT and related studies demonstrated that the then to-date perseveration in the United States on ethics and advance directives was largely ineffective in improving care for the dying. SUPPORT suggested a need for a new direction and a new emphasis on systemic change. The message, quite simply was, "if you want the system to change, you have to change the system." This message also applied to education. Like advance directives, education in a vacuum is not terribly helpful, as I painfully discovered after giving many noon conference presentations to housestaff to negligible effect. Education still played an important role, but educational reform must be integrated within larger efforts at systemic change.

Work within the System

As it turned out, I was lucky to be employed by one of the largest health care systems in the world, the Department of Veterans Affairs (VA). The VA historically had played a major leadership role in promoting geriatrics as an emerging specialty of medicine in the 1980s. It was my hope and the hope of many colleagues that similar leadership could be provided for palliative care. The VA serves a large, elderly population. Approximately 29% of all Americans dying each year are veterans—an estimated 650,000 veterans die every year. So the need for palliative care in VA is obvious. The VA has been an exciting and at times challenging health care system within which to work. While VA leadership in Washington has been very supportive of palliative care, the same cannot be said for all leadership at local levels. While some have truly embraced palliative care, others have been more cautious in their support. Like their private-sector counterparts some local leaders remain unconvinced that investing in palliative care will yield a positive return clinically or fiscally. So we still have some work ahead of us. Still, I am pleased with what has been accomplished to date and am optimistic about the future.

The Grand Experiment

In reflecting back over the past 10–15 years of my career it seems that palliative care in the United States is involved in a grand experiment. Gandhi once wrote, "We must become the change we want to see." True, but turning the statement on its head we might ask, "Must we become that which we wish to change in order to change it?" Will we as a social movement be able to change the health care system through deeper integration with it or might we ourselves be changed by the system in ways contrary to our vision? In 2000 under the auspices of the then recently formed Center to Advance Palliative Care (CAPC) a pivotal meeting of physician leaders was held, which addressed the key question—whether we should push for subspecialty status for palliative medicine. This meeting really represented the start of our drive toward such status. A vigorous debate ensued, revolving around this question. Was this an effective strategy for change or, as one contrarian in the group put it, would we be "co-opting the revolution," and just become just another cog in the greater bureaucratic healthcare machine? While mindful of this peril, I believed and still believe it was worth the risk to try. However, I think we do ourselves no favor if we minimize the gamble we have undertaken. Efforts toward accreditation, certification, and related competencies may be necessary, but they also carry with them inevitable bureaucratization and with this the real danger that we will lose a certain revolutionary zeal. More importantly, we may forget why we got into this business in the first place. I think many leaders in palliative care of my generation were drawn to the field for three key reasons:

1. We "got it" that the health care system was seriously flawed.
2. We wanted to change this system and palliative care seemed like one good avenue toward that end.
3. We tended to be independent cusses, who enjoyed rabble rousing.

For many of us, certainly me, the current evolutionary phase of palliative care, which seems to be rather preadolescent in its perseveration on rules, competencies, and measures, may be necessary, but it is also frankly irritating and tiresome. I can only hope that others have a greater tolerance for it than I do and that the field can grow beyond preadolescence and adolescence into something resembling adulthood.

Toward Adulthood

So, what might adulthood look like? My hope is that palliative care will be accepted both as a specialty and an integral aspect of all medical care. We will have transcended our current fears, our insecurities, and our efforts to prove our collective worth. Ultimately, I hope that the very special work we do will be seen as nothing special, just good medicine.

Lessons Learned

The editor for this series, my good friend V.J. Periyakoil, suggested that authors share some "tips" or lessons learned that might be of help to others. In no particular order:

- **Read books related to palliative care.** The most valuable reading I have done is in books, not journal articles. The modern tendency to short, "sound-bite" packaging of information is useful for some things, but is also a threat to the more complex, thoughtful analyses necessary for a deeper understanding of palliative care.
- **Go where you are not supposed to.** My work in intercultural communication really started when I was in the

general (not medical) Stanford bookstore. I wandered into the anthropology section and a title with "intercultural communication" in it caught my eye. I found the topic highly relevant to what we are trying to do in palliative care, but the literature was virtually unknown within our field. Linking the two, it was relatively easy to become an "expert" in the field, given I had no competition.[6]

- **Courage in rocking the boat is an underappreciated value**. Harder still, it takes courage to be patient and work with others in trying to change the boat's course.
- **Keep a healthy balance between the big and small stuff**—one is not more important than the other. Every night after work, I return home, where my daughter, Mika, who is disabled from birth, is waiting for me. There are meals to be fed, baths to give, and diapers to change. Caring for my daughter keeps me grounded and reminds me why we do what we do. Big or small, we are all in the same soup.

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