

THE WALL STREET JOURNAL

August 31, 2004

On Death and Dying

By Abraham Verghese

In the early years of the AIDS epidemic, when effective drug treatment was just a dream, many of us in the field of infectious diseases found that our work revolved to a large degree around the care of the dying. It was not something we had anticipated.

In asking how I could best care for my patients who were dying (and dying of a disease that stigmatized them) I inevitably came to the work of Elizabeth Kubler-Ross. Of course, I knew her name and knew of her "stages of grief" -- denial; anger; bargaining; depression; and acceptance. Such knowledge was part of pop culture, a likely question on Jeopardy. But like most people who invoked her name at a cocktail party, I had not actually read her book, "On Death and Dying."

I was in for a tremendous surprise. In the first place, the style was inimitable and personal. Here was a writer who told compelling stories, who used humor and vivid anecdotes, and whose writing was based on hours of close observation of hundreds of patients. Strangely, the fact that she was a doctor was not detrimental to her work, by which I mean that her authorial stance was so closely allied with the patient, so much in the patient's shoes, that she had found a perspective, a narrative window, that would have eluded most physicians.

At one level she was writing for doctors of her era who felt they did not have much of a role at the deathbed. Indeed, her peers viewed her as an eccentric, a troublemaker. It was a time when patients were not always told if they had cancer. In the hospital, death was so medicalized, so intruded on with technological interventions, that all its emotional connotations were effectively removed. But death, like sex, happened for the most part at home and behind closed doors and was not a subject for discussion. Here Kubler-Ross was propping the door open. It did not earn her tenure at the University of Chicago.



AP/Wide World Photo

Elizabeth Kubler-Ross,
thanatologist

"On Death and Dying" appeared in 1969, and seemed more germane than ever when I read it in the mid-'80s. The subtitle captured its strength: "What the Dying Have to Teach Doctors, Nurses, Clergy and their Own Families." I had already discovered that even if I thought I had little to offer my patients dying of AIDS, they had a great deal to offer me. They instructed me; they ministered to me. My coming to their homes, to their bedsides, and seeing them with their family was enough, they seemed to say. I was rediscovering what the old horse-and-buggy doctor of many years before had known: When one has no cure, one can still heal, by which I mean a coming to terms with death, an acceptance of it by patient, family and yes, by the doctor. Above all, the dying did not need to be isolated, or worse, institutionalized, when the pain relief or other care they needed could be provided at home.

The "stages" Kubler-Ross described were sometimes taken too literally, and I remember well-read family members asking me what stage I thought the patient had now arrived at. The labels did not matter (and I suspect she would have agreed); it sufficed to know that acceptance of death was a place most (but not all) patients would get to, and that they could for good reasons feel denial, anger, an urge to bargain, and depression along the way.

Elizabeth Kubler-Ross died last week at the age of 78, after some years of living with infirmity.

Her various books and her other interests in later life (including her preoccupation with the afterlife) did not surpass the power and influence of "On Death and Dying."

Kubler-Ross's seminal work facilitated the acceptance of the hospice-care movement which was introduced in this country by Dame Cicely Saunders. Nowadays, most patients with a terminal condition are eligible under Medicare for home hospice care. In the last decade or so we have seen the emergence of the specialty of palliative medicine whose focus is on patients with life threatening, incurable and progressive illnesses. The palliative-medicine team's goals are to render the patient pain free and improve the quality of their life, goals that are quite different (and reimbursed differently) from the usual physician's goal of curing disease and saving and prolonging life.

The comfort needs of patients dying at home are now obvious, and hospices abound. But palliative care even has a place in the seemingly incongruous setting of the intensive-care unit, that gleaming tabernacle in which we house the high-tech instruments that save and prolong life. However, death is no stranger to intensive-care units, particularly in patients with cancer, and more so if they are on a ventilator. The goal of cure and prolonging life is not at odds with the goal of relieving suffering and reducing symptoms. The two efforts can occur concurrently.

At the heart of Kubler-Ross's proselytizing for so many years was her concern for the patient, her wish that every physician be able to fully imagine the patient's suffering and act accordingly. She wrote: "If we can teach our students the value of science and technology simultaneously with the art and science of inter-human relationships, of human and total patient care, it would be real progress." It is a balance that all of us educators struggle with. I think she would be pleased with the progress we are making.

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