

“IN THE ROOM WHERE IT HAPPENS” (from the play “Hamilton”)

Chit Chat Club Essay

Michael Thaler

June 13, 2017

“Two days before he was scheduled to die, John Shields roused in his hospice bed with an unusual idea. He wanted to organize an Irish wake for himself. It would be old-fashioned, with music and booze, except for one notable detail — *he would be present.*” Thus begins an over-the-fold front page article in the New York Times of May 28, 2017. On the day of his death, scheduled and orchestrated by himself and his wife, John Shields’ dying wish was: he wanted to be in the room where it happens.

The desire to participate actively in one’s departure from life was not at all unprecedented, or even news. The newsworthy part was the article’s celebratory tone, under the headline **At His Own Wake, Celebrating Life and the Gift of Death**, and the fact that it was deemed worthy of occupying most of the front page and 4 entire inside pages, lavishly illustrated, one photo even showing Shield’s wife and his doctor as they completed forms for her patient’s medically assisted death.

I chose medically assisted dying, or MAD, or euthanasia (the good death) as it is frequently called, for my topic because it has clearly become timely (pardon the pun), brought even closer to home by the passing in just the past few months of three esteemed members of the Chit Chat Club, Judge Schwarzer, Judge Noonan, and the Honorable Kevin Starr (the latter 2 also commemorated in the New York Times). The recent passage of the End of Life Option Act by the State of California last summer, only the 4th state to

pass such legislation after Oregon, Washington and Vermont, also adds immediacy and reflects this rising trend. From the physician's perspective, I have had to deal with aid-in-dying in my lectures on Medical Ethics to fellows and residents at UCSF.

Finally, I have participated every two months for some 20 years, at informal meetings in Berkeley with an eclectic gathering of professors, practitioners, graduate students and writers who style themselves the Death and Dying Pot Luck Club. Speakers are invited to address some aspect of death and dying, and rewarded with a T-shirt emblazoned with "I survived the Death and Dying Potluck Club." Ironically, or perhaps predictably over these 20 years, the Death and Dying Club has seen its membership depleted by death and infirmity, much as the Chit Chat Club has, and like the Chit Chat Club, keeps replenishing its ranks.

When I had the opportunity to address the Potluck Club some 15 years ago, I focused on choices made by 3 men stricken with the same fatal disorder, how they had chosen to die in a way which reflected the highly individualized manner in which each had lived. My talk featured the deaths of these terminally ill individuals recorded on film: one 79 years old, one middle aged, and one closer to his prime. All 3 were afflicted with amyotrophic lateral sclerosis, ALS, Lou Gehrig's disease; all had chosen to die assisted by a friend or a physician. The takeaway of the presentation was that doctors who deal with death on a daily basis, in intensive care units or on cancer wards, tend to set aside their usual concern with personalized care when confronted with a dying patient, using instead the depersonalized label "terminally ill". Way back, before the 1960's

introduced the more objective “terminal patient”, the label for an intractable condition had been “the hopeless patient”. The message I presented to the Death and Dying Club was that the patient was neither “terminal” nor “hopeless”, the disease was. To illustrate the point, each of the three men stricken with the same disorder had selected a different means and manner of dying. So I was surprised, pleasantly, I must admit, when I read in the Times article that the physician who assisted Shields had already attended over 35 deaths, “each intimately different from the next”.

Now a bit of about the 3 patients stricken with ALS. The oldest had become famous during the final year of his life. (You all remember Morrie.) Morrie was interviewed by Ted Koppel on Nightline three times in that year of 1995 before he finally decided he’d had enough. He was subsequently celebrated in the bestseller **Tuesdays With Morrie**, which remained on top of the charts for over 2 years. This overwhelming reception indicated that the matter of how we choose to die had become a topic of great public interest in the 1990’s at least in this country. Morrie was a soft-spoken, endearing professor of sociology at Brandeis University who had announced between increasingly labored breaths as the months went by, “My dignity comes from my inner self,”, i.e. not to be dragged down by all the life-support paraphernalia around him. Nearing the end, he admitted that “his soul, perfectly awake, was imprisoned inside a limp husk of a body.” I can still visualize that withered husk leaning sideways in his wheelchair, Stephen Hawking-like, surrounded by his beloved books, one of which stood out even on that crowded shelf - Sherwin Nuland’s National

Book Award winner “How We Die”, another blockbuster in the genre. Nuland, who practiced surgery at Yale’s School of Medicine, and had published his book that same year, 1995, argued that we tend to aggressively over-treat patients whom we can no longer provide with a “life worth living”. I met briefly with Nuland a few years later, in the early 2000’s, at a conference of the American Association of the History of Medicine. He sought me out after I had presented some research on medical ethics and the dying patient. As I recall, we exchanged some thumbnail thoughts about the key issue, at least as far as I was concerned: who was to decide whether a life was worth living or should end: the physician, the patient, or the family. As it turned out in the years since, it’s all of the above. (“Whose life is it anyway?”, with Nancy Sniderman).

The second man was what is often described as a *character*. He differed dramatically from John Shields - the civically engaged, accomplished 78-year old union activist featured in the NYT article - yet the two shared the same need to welcome death with a celebratory event resembling an Irish wake, surrounded by friends and former drinking buddies. This was a tough, tattooed Vietnam veteran, prominent member of motorcycle gangs, whose most treasured possession was a collection of old license plates from bikes he had wrecked over the years. Stricken with ALS, he raged when his Puerto Rican nurse, a devout Catholic, sneaked a picture of Jesus onto the wall facing his bed. “Get that fucken thing out of here,” he swore, sucking for air as she begged him to let her pray for him. “No way am I going to catch religion at this point!”, he gasped, reminiscent of the famous iconoclast and atheist Christopher Hitchens on his deathbed. When the

weeping nurse ran from the room, he had a change of heart, pressed the button that called her back, and conceded, “Alright, you can leave it up there, and it’s alright for you to pray for me, as long as it ain’t me”. Somewhat later, surrounded by a boisterous crowd at his “wake”, he waved “Goodbye everybody. See ya’!”, had himself wheeled back to the bedroom, and with a benign Jesus still looking on, drank the hemlock concoction handed to him by a friend.

The third was a 52-year old Catholic antique car collector, whose death was displayed on the CBS program 60 Minutes in November, 1998. The patient had decided not to become a burden to his wife and family – to seek an end while he still had most of his faculties intact – and the family agreed! Millions watched, in the greatest act of voyeurism ever, as he slumped over in his chair immediately following injections delivered by Doctor Jack Kevorkian into the man’s arm. His wife informed the vast audience that her husband had lost the use of his arms and legs, suffered greatly from pain, and choked on his saliva. “I consider it [his death] humane. I consider it the way things should be.” As everyone knows, Kevorkian, or Dr. Death as the press had crowned him, had been a pathologist in Michigan who had made a career of dispatching patients through a hookup he had labeled the Thanatron, a Death machine.

Public acceptance of euthanasia for patients with irreversible coma due to severe brain damage rapidly increased in that decade, propelled by the Terri Schiavo case, a young woman in a persistent vegetative state kept alive while in a coma for 15 years. In 1998, her husband petitioned the Florida 6th Circuit Court to remove her feeding tube, but was successfully

opposed by her parents for 7 years with appeals through the state and federal system. Schiavo took 13 days to die after all nutrition and hydration had been discontinued, an instance of “active” or physician-administered euthanasia, compared with the examples of “passive” or physician-assisted euthanasia described above. Meanwhile, the Hemlock Society and other special interest groups, promoted “Death with Dignity” for a growing number of patients with intractable cancer, ALS and other fatal disorders. Increasing longevity, combined with improved methods of intensive care, multiplied the numbers of patients who slowly but surely drifted toward a difficult death.

In response to the growing demand for end of life care, to ease the pressure on overwhelmed intensive care and oncology units, and to provide patients with professional palliative support in the last 6 months of life, the Hospice movement based on a model adapted from St. Christopher’s Hospice in London, England, accelerated rapidly in the 1990’s. Funding from Medicare and insurance agencies soon followed public demand.

Legislative support for physician-assisted dying or suicide programs was much slower in coming. The main driver behind the very gradual, but inexorable, acceptance of doctor-assisted death by physicians, was the revolution in medical ethics which slowly eroded traditional opposition to the very idea of a doctor “pulling the plug”, let alone actively facilitating the death of a patient. For at least 2500 years, the stout pillar of the medical profession has been Benevolence toward the patient, as codified since the time of Hippocrates in the “Above all, do no harm” oath, or, in other words,

do good. Remarkably, and with astounding speed, the foundation of medical ethics, benevolence, was dethroned in the 1960's cultural revolution, which above all else, was a challenge to figures of authority in every area of social life. And the benevolent, but powerful figure of the male physician was suddenly perceived as paternalistic, domineering, and most challenging of all, not to be trusted. Dr. Welby took a steep fall.

Almost overnight, an internationally acclaimed study of syphilis which had been conducted without incident since 1934 by public health doctors using black subjects in Tuskegee, Alabama, hit the front pages as unethical and, worse, racist. As if out of thin air, injunctions from the Nuremberg Trial of Nazi Doctors were put forward as models for American physicians doing research on human subjects. Such a connection would have been inconceivable while the actual trial was in progress just two decades before. The first and most important of the 10 legal injunctions, ("majestic", Katz) which have since been enshrined among ethicists as the Nuremberg Code, states: "The voluntary and informed consent of the human subject is absolutely essential". Now you know why you get to sign so many unreadable forms each time you go to a clinic, enter a hospital room, leave an emergency room, or even see a doctor.

By the early 1970's, a group of newly anointed moral experts (and I do mean anointed, as many had been priests, such as our own Al Jonsen) expressed and codified the new egalitarianism. They called themselves bioethicists, who met at Georgetown University, and came up with the 4 core principles of modern medical ethics, generally known as the Georgetown Mantra: 1. Patient Autonomy or Personhood; 2. Beneficence;

3. Non-maleficence (explain); and 4. Justice (Fairness). Every medical student, intern and resident has the Mantra drilled into them. In dealings between physicians and patients, these 4 ideas have assumed the status of medico-legal and moral commandments.

Nowadays, American physicians regard the patient's informed consent as the core part of any therapeutic encounter; the patient's wishes (Patient Autonomy) the cornerstone of the modern patient-doctor relationship. Accordingly, it follows that the physician is psychologically and legally prepared to assist the medically unsalvageable patient, to help him or her find an "easeful death", a felicitous phrase I borrowed from Shakespeare to describe the new therapeutic challenge. Patient Autonomy now trumps Hippocratic Benevolence.

What are the criteria that mark the patient who is eligible for physician-assisted suicide in California? The End of Life Option Act, as it is known in this state, was signed into law by Governor Jerry Brown, a former Jesuit priest, in October, 2016. Under the law, a patient who requests lethal medication from a physician, must be a California resident, at least 18 years old, **mentally competent**, and terminally ill, with no more than 6 months to live. The determination of the patient's medical status must be made by two physicians licensed in California. The requirement for mental competence has become increasingly controversial, as it leaves patients with Alzheimer's and other forms of advanced dementia to linger for years, "without the ability to experience life meaningfully, to engage or even recognize loved ones and interact with others, to participate socially, or

pursue personal interests at least at a minimal level” (quote from an advocate).

In anticipation of the physician-assisted dying law, a new medical specialty has arisen in California, as yet unorganized and uninstitutionalized, of physicians who have limited their practices to preparing patients for their inevitably approaching end, to prepare the injectable mixture of medications, mainly secobarbital, antiemetics (drugs against nausea and vomiting) and a tranquilizer, and help self-administer the lethal suspension. The drugs cost around \$5,000. MediCal will cover the cost, Medicare and private insurers are still scratching their heads about it.

I once taught a course on alternative medicine for Elderhostel, now known as Road Scholar. The program included a visit to the newly established hospice in Laguna Honda Hospital. The entire 3rd floor had been taken over by specially trained nurses, handpicked by the director, a physician who had left a position on the faculty of Harvard Medical School for an opportunity to build a facility for terminally ill patients, formerly known as hopeless patients, according to his specifications. The hospice at Laguna Honda featured a central meeting area where patients and visitors could meet, a kind of living room with cozy, old-fashioned wooden furniture, a space for artistic work, and a private room set aside for the acutely dying patient - what the director called his “intense care unit”. The window of the bright sky-blue room overlooked an oriental garden with a small but audible fountain.

The day we visited, a man named Roberto was nearing death from prostate cancer. He had worked as a porter at the Fairmont Hotel since the days of his youth in the Philippines, and had expressed a wish to revisit his native village before dying. The director explained why this was impractical, but suggested a way to revisit the days of their youth to Roberto and his wife, his teenage sweetheart.

When my group arrived, an easel had been set up in the middle of the living room. The pair was deeply engaged in drawing the main street, the church, and the school they had attended in their village, finally fitting in their homes and the faces of long forgotten and now freshly recalled friends. They discussed and argued over every item, and by the time they finished they felt they had come home in a way they never could have in reality. The other patients, the visitors, and the staff, everyone applauded as the work was completed and displayed on a wall. Three days later, Roberto died in the “intense care unit”, with his wife at his side, listening to his favorite Philipino melodies against the soft whisper of the waterfall outside his window.

It helps if you are in the room where it happens.