

'Cure sometimes, relieve often, comfort always'

One of our dear friends has just turned 80. "S" is one of the smartest people I know – a social scientist who still does research, serves on a hospital's ethics review board and is co-director of her condominium association. Until recently she could walk miles, and she swam regularly. She is now quite ill.

Her life and medical history illustrate a profile of medical practice in the 20th and 21st centuries. As a child she suffered what we physicians once called "usual childhood diseases": measles, mumps, chicken pox, rubella, whooping cough – diseases now unusual, thanks to vaccinations. She had her tonsils and adenoids removed, an operation ("T and A") much less common these days, although some of us fondly remember the post-op ice-cream treat. She also came down with rheumatic fever for which she was put to bed for three months and forbidden to play sports afterward. Her sister contracted tuberculosis.

After the birth of her daughter, S suffered for two months with severe pain in the abdomen. Her physician called it "neurotic, first-child syndrome." It was a midwife who recognized the pelvic infection. Surgery followed but left her infertile at a time when she and her husband were ready to have more children. Friends urged her to sue for malpractice, but she declined — lawsuits weren't so frequent in those days.

A few years ago, after her husband died, she passed out from an irregular heart rhythm and needed cardiac surgery. If that weren't enough, she has since developed glaucoma, hearing loss, cystitis and vitamin D deficiency, and more recently some kind of lung infection resistant to treatment.

But her worst affliction, which began in her 30s, is osteoarthritis (also known as degenerative arthritis), a condition where the cartilage in the major joints wears down. Without the cushioning cartilage provides, the bones simply crumble. To repair a hip joint in the old way, a metal replacement was glued in with a kind of cement. S was allergic to that chemical and the replacement came loose. It took a total of four operations on her left hip, three on her right shoulder and one recent surgery on her right hip to get things right.

But the result of all the surgeries has been an unremitting pain in the head and spine for which ordinary painkillers are either ineffective or leave her feeling "loopy." She takes small doses of an anti-anxiety drug to help her sleep, but one of her too many physicians commanded her to stop taking this "addictive" drug.

"Imagine," S says, "telling an 80-year-old woman to suffer insomnia instead, just to practice 'perfect' medicine, it's insane."

What I also find remarkable is that in this age of supercomputers and discovering the origins of the universe, no physician — none — had access to her complete medical record; in fact, it still doesn't exist beyond this essay. She has no single family physician.

As she grows older, fewer organizations call on her to lend her professional skills and experience, friends are dying off, her children and grandchildren live far away, she lives alone. As revealed by her own research on family and work: "Our culture is so fragmented in every way, each element out of sync with the other elements." Indeed, she notes the parallel between a fragmented medical system and how her physicians fail to recognize that illness in any part of the body can affect one's entire health. Each physician pays attention only to his own specialty organ.

To be fair, there is one other difficulty: S is not shy about expressing her opinion, and she demands that her physicians explain things, that they listen to what she has to say. With such a patient, some physicians believe their authority is being threatened. Others engage in a "rescue fantasy," taking it as a challenge to cure the complicated patient completely. Thus if the patient remains ill, they tune out, or refer the patient elsewhere. One internal medicine specialist gave up on her entirely.

S is in constant pain. "If I could end it now, without my children knowing that I did," she says, "I would do it." Doctors and others in our wellness-driven culture, she says, have a "mad, mad way of looking at death, but some people don't want treatments that make them even more miserable; or they try to keep you perfectly well no matter where you are in the course of life." It was a 19th-century poet, Arthur Hugh Clough, who wrote, "Thou shalt not kill; but needst not strive officiously to keep alive."

Poetry. Some medical schools and teaching hospitals have initiated seminars in poetry for busy medical students and residents, such as the one directed by Dr. Jack Coulehan at Stony Brook University in New York. He wondered how, under our modern, technological and bureaucratic medical system, a patient could get "an attentive and sympathetic hearing," from the physician.

Perhaps physicians can gain empathy by studying poetry, which, he says, "lies at the core of cultural healing traditions throughout the world." Moreover, poetry requires an attention to language — how language can hurt, but also how language can heal, uniting "tenderness with steadiness." As my wisest medical professors used to teach: "Cure sometimes, relieve often, comfort always."

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