Reflections In Family Practice

A Good Death Is Hard To Find: Preliminary Reports Of A Hospice Doctor

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The telephone rang as I brushed my teeth, slipped into an overcoat, and sprang down the stairs for choir practice. It was the hospital. "Sorry," I snapped, "not on call."

"But doctor, I thought you'd like to know that Mrs. Johnson in Room 203 just expired." Alice Johnson was a hospice patient, her death sudden but not unexpected, and I politely thanked the nurse for her call. But before I could hang up, she continued, "Mrs. Pauling in Room 201 also passed away. Both precisely at 6:55PM; we were with them when they died!"

I was startled by the coincidence: two of my patients, occupying the whole of the newly inaugurated hospice wing, ended their lives synchronously. I flipped a familiar mental switch, one that cancels plans and shifts expectations, and acquiesced to the more urgent need. "Tell the families that I'll be over," I said, and headed for the hospital, ruminating on the Divine Hand that leads us to the heart and soul of experience.

Alice lay twisted in bed exactly where her husband and the nurse had lifted her. As Hugh would tell it, she had felt gaseous and sick, motioned for the commode, but once there turned ashen, clutched her throat, and gasped a final breath. No time for nitroglycerin, Hugh hollered for more nurses, more doctors, *anybody*, as his wife became unresponsive and suddenly still. I found him crouched beside her, dazed, and so extended my hand and a few fumbled condolences. Her sisters had gathered, too, and I hugged them and offered my sympathies. It was a blessing, we agreed, for her to have passed so quickly from this earthly pain. Hugh accepted my handshake but immediately launched into his familiar tirade.

Doc, I'm not mad at you, it's just what this country has come to, when you can't do anything for a person's pain or even find out what's causing it. I spent $300 on a specialist in Saylorville — paid out of Medicare's pocket — to learn I would have to live with my dizziness, when he knew all along that there was nothing he could do, because all the other people from town who went to him were told the same thing. We're right here in the middle of the hospital, and you can't get a doctor to help when you need one, not that it would have done any good, but if we would have been at home at least I could have called the doctor to come, not that it would have done any good . . . .

Hugh's voice trailed off in an effort to swallow his hostility, to avoid offending me further, and to cloak the bitter, lonely core of the man he had become or perhaps always was. Alice was his last link to the world, and now her death sealed him in bitterness and alienation.

The hospice team had tried to reach Hugh through two agonizing family meetings, countless home visits, and belabored discussions at my office. His shield was anger: the world had let him down. Alice had somehow made her peace with it. She locked herself away, kept her opinions and feelings and longings inside. The accelerating, inexplicable pain of these final weeks isolated her even more; it distracted us and invited escalating doses of morphine.

In the adjoining room the 3 children had kept vigil all day. Their mother had trembled with fever spikes and focal seizures. They noticed, within Vanessa's cherubic face aflush from steroids, her darting eyes, widening pupils, and frantic efforts to raise herself before the nurse pushed the last bolus of meperidine. Vanessa relaxed and expired with a slow final squeeze of the bellows. The children brought up the covers snugly, as they had done so many times before, even during the last hours of the scorching fever.

Katie, the eldest daughter, had been right about her mom, what she said in the hallway just this

Submitted, revised, 9 March 1993.

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morning: "It's good for her to be here, to die here. She deserves it, this fancy room, all the extra attention."

I thanked her for the compliments about our hospice wing and expressed my own gratitude for the hospital's gift to the community. But as I listened, she was thanking *me* for something, something she also found in the nursing care: our simple expressions of love. I hugged them all (save Gene, the barrel-chested, beer-bellied son) and felt an overwhelming rush of affection and admiration for this ordinary hard-working back-country family. They had struggled for months with their mother's brain tumor, shuttled her to doctors' appointments and radiation treatments, juggled the kids' summer activities and the start of school, somehow maintained an antique business, and dealt bravely with their own complex feelings about a "providing" mother who had difficulty baring her emotions or expressing love openly, in a caress or hug.

Through it all, Vanessa was kept in the middle of the domestic flow of traffic, snoring in her Lazy-Boy chair next to the wood stove in the parlor. She was always the first to be hailed or hollered a goodbye as her family hurried through the front door. Katie had requested the hospice wing only for these last 8 days, as her mother's life began to flicker.

Against this backdrop — the buckling impact of contrasting deaths — I came upon a curious title in the family practice literature: "Toward a Good Death: An Interpretive Investigation of Family Practice Residents' Practices with Dying Patients."[1] The authors had undertaken a study of residents' emotional responses to the impending deaths of their patients. It both delighted and disturbed me, fanning forgotten memories of my residency training and rekindling my profound sense of inadequacy to cope with the spectre of an impending death. During 1 week, while I was the senior resident on the inpatient service, 3 of my patients died. I felt abandoned by my attending physician, incompetent to care for the seriously ill, and suddenly embarrassed by my collapse of confidence. The study accurately reflects, I believe, the terrible anxiety residents feel as their patients cross the forbidding divide between life and death.

On another occasion I was chastised for not going to a patient's home to pronounce him dead. *That*, it was explained to me, is what family doctors do. Sometimes I go now, bound not by law or a sense of obligation, but for the sacramental opportunities that abound there. No one ever pointed these out to me; no one helped me into the chasuble and stole.

The Santa Rosa residents could recount only two examples of a "good death" among their 31 dying patients. But the odds were stacked against them. In residency, and often there for the first time, physicians come to know death intimately, tragically, responsibly. The deaths are vaguely familiar — is it our father, another patient, ourselves? — but the trappings are not. Strange diseases, rigid expectations, marching time. I was not surprised by what the residents said about their patients: "No one could deal with the situation, and [everyone] avoided his room." About the families: "It can be so painful that it can drive you to the point of feeling you must forget them, like you can't ever see them again, like you can't talk to them again." About themselves: "Death is a sign of my incompetence, the ultimate failure. I've been trained to go ahead and prevent death." But I was shocked to learn that "no one in the hospital talked about the nonbiomedical aspects of dealing with dying patients." Where were the attending physicians, if not at the patient's bedside, or comforting the family, or supporting the residents during their tribulation?

Toward a good death. The phrase stuck in my throat as I tried to make sense of that evocative evening on the hospice wing, the double curtain call for those contrasting lives. I am not sure what constitutes a good death. The authors did not define it. I lack the convictions of my fundamentalist friends, who would cast the Grim Reaper in a cameo role and swing their spotlights to the eternal reward. Growing up in Iowa, I learned that people died of natural causes, and natural was somehow good. Even when my father died of a heart attack at the age of 48 years. Coronaries ran in the family, like his cigarette-smoking and his midriff bulge and his sedentary ways.

Once I entered the university hospitals, I saw life's unraveling through the jaded eyes of a physician. People died of complications, and complications were, well, complicated. My appreciation changed not so much because the times did, or because I moved from the loping pace of the Midwest to a faster, more sophisticated East, or because nostalgia sweetened my childhood memories. My *community* changed, from a rural farming population to a towering, technological, medical bureaucracy.

My community has changed once more, back to a small working-class New England village. Once again many of my patients are dying naturally. Some have died at home, surrounded by their families, suffering no undue pain or worry, accepting their universal fate and bringing closure to their lives. But other recent deaths have left haunting, irreconcilable memories for their survivors: the stillborn son of our close friends, the shotgun suicide of a disturbed adolescent, the schoolmarm who withered away in her melancholia, and the victim of facial cancer who died in the saddle, still leading the charge of chemotherapy. God bless Hank — one of my favorite patients — who would not give up until that last teary embrace, when his wife squeezed her blessings, and he turned his back on the pain and ignominy of that disfiguring disease.

And what would you say of Alice Johnson? What goodness can be found in her implacable suffering, in her undignified death on the commode, in the rantings of her husband, lost to anger? She reminded me of the old woman in Sherwood Anderson's "Death in the Woods,"[2] who froze to death in the deserted clearing, half-clad, far from home, surrounded only by the primitive, mournful wailing of her dogs. Or Vanessa Pauling, who died in peace except for that one haunting moment when her eyes flashed the words of Kurtz, Joseph Conrad's antagonist in *Heart of Darkness*[3]: "The horror, the horror." How would I explain that unmistakable look to the family? Would I lie and say with utter certainty that it was only the last physiological rush of adrenalin before the machinery seized?

I have no assurance that any of my patients have died a "good death." The notion itself probably reveals more about our own needs and mental categories than those of our patients. It is longing for an easy death in an age of convenience. So I withdraw all conclusions and attend to my patients' needs as best I can. My role is often clumsy and unheroic, like Gerasim in the service of Ivan Ilych,[4] who sat with his dying master despite the unsightliness of his decay and comforted him by lifting those withered legs upon his own broad shoulders. I know that I cannot create a good death where there has been "no real pleasure in life," as the Grandmother learned in Flannery O'Connor's short story about "The Misfit,"[5] who slew her family one by one despite Grandmother's appeal to his "goodness at heart." The goodness of death is a matter for patients to decide after settling arrears with their Maker.

The least I can do for my dying patients becomes the most: choose not to abandon them, acknowledge their suffering, guide them on the journey's end. Ours is a supportive role. We are Sherpa guides whose strong backs and ready knowledge of the "conditions" will prepare a climber for the final ascent. This method, this mercy, must be learned and taught by example. We discover it in a painful presence at the deathbed; in the awkward goodbyes we exchange when our relationships rupture[6]; in the mutual support we provide each other — physicians and caregivers and families alike — in hopes of surviving our losses. Dying within community. Creating communities, such as hospice, in which to die.

Good deaths are often tangled in complicated webs, and bad deaths come as naturally (that is, inevitably) as the next. Why not abandon our categories altogether, suspend the judgment, break off our detached and empathic gaze? We would do well to check our stethoscopes at the doors of the dying and fix to stay with them awhile, listening. We might be surprised by what we hear *inside* us. Is it our own anxiety, or sorrow, or perhaps a thin yet invigorated call to service, that voice that was calling us from the start?

Few patients will die "like they're being rocked to sleep in their mother's arms," contrary to the claims of a Santa Rosa physician.[1] And for these patients, our presence makes little difference. The challenge, the reward, the mystery lie more with persons like Hank and Alice, who will cling to us, test us, and leave us with their frayed ends and unfulfilled desires. Perhaps it was for them, too, that Dylan Thomas[7] penned these lines:

> And you, my father, there on the sad height,
> Curse, bless, me now with your fierce tears,
> I pray.
> Do not go gentle into that good night.
> Rage, rage against the dying of the light.*

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