DoubleTake Magazine

Hospice and the Intangible Wonders of Being

Mary Josephine Mahoney

In 1993, my interview to be a hospice nurse in Houston, Texas took place in a vinyl doublewide on a lot of prime real estate in the southeastern medical district. Two hundred yards uphill, the construction of an inpatient facility had just been completed. A three-story Tudor replica of the original Hospice estate building awaited its grand-opening on a deep green lawn behind black iron gates. That Thursday afternoon promised a ceremony with the pomp of Texas-old-money and down-home charm. Velvet ropes and balusters lined the porticos. Yellow ribbons flapped the uprights of the brick archways. I attended the opening with Sally Kane, the director of nursing, whereby ceremony's end we clinked our plastic champagne glasses to my "joining the *outpatient* team."

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The brooding sky on that September afternoon crackled and hissed, but the CEO stood waiting for the guest of honor with his scissors ready and a cordless microphone pinched on his lapel. When the Bush limousine crawled in on cue, the Wales-born CEO spoke hearty Texan to the well-heeled crowd of trustees and benefactors. "Perhaps the raindrops are tears of compassion," he said. A minister and a rabbi both led a prayer. The founding doctor stood long and straight in the receiving line by the podium, his fingers clasped in the weave of a simple basket. In his navy suit, this tall and pale doctor with jet-black hair made many nurses think of the young Abe Lincoln. In these circles, our Abe was a local

messiah since he had pioneered hospice services to the city. Fourteen years prior, two charitable and visionary sisters of the Carmelite Order rented out a vacant wing of a convent to him for ten dollars a month. From this collusion, the legacy began.

Abe gave the formal dedication of our oath and vision. He sprinkled his tactful address with seedlings of layman's Zen. After Abe spoke, Barbara Bush stepped forward in a serene, teal suit, joined hands with the CEO and said an effectual kindness. They two hewed the yellow ribbon. The ribbon gave a brief snap and fell on the crimson bricks of the ambulance circle.

The community saw this at six o'clock on *NEWS 2 Houston*.

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In 1993, the Houston elite changed the care of the dying from a marginal social cause to a sanctioned one because compassionate care of the terminally ill had arrived as a prevalent ideology for those of great means. The clemency of the rich would put us on the map, even our itty-bitty, twenty-four-bed institution in the tangle of Houston where teaching hospitals and charity hospitals freckled avenues as predictably as car dealerships.

The edifice alone, the Suits purported, could channel even more clients and donations than the *Candlelight Ceremony* on New Year's Eve. At night, the satin sheen of masonry under soft yellow floodlights would connote a very sound pedigree to passers-by, who headed undoubtedly to the miasma of the cancer center where the riskiest lymphomas and insulin-producing tumors were treated but not necessarily cured.

The building alone would keep us fat with money. Since the mid 80's healthcare crisis, there was little to no chagrin left among healthcare executive officers. At *The Hospice*, when they spoke the high language of profits and ventures about a service to the dying, our wise receptionist would draw the pocket doors of the meeting room to keep their words from reverberating through the public hallway.

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In design, the new Tudor was a close cousin of the red brick, estate house adjoined by a bridge that overlooked a peace garden. It would house twenty-four inpatient rooms, respite for patients whose pain ran wild or families needing relief. The two floors also sported dining rooms, a media-conference room, two lounges, a supplies facility, a

pharmacy, and a state of the art therapeutic bath tub in a room with womb lighting that would be used only twice in the next two years. The tub was so low and deep the nurses could not lift a frail patient out of it. A whole security station, and of course, more executive offices. At the ribbon-cutting ceremony, rumor had it that a malingering fight among the administrators had settled: the seven thousand square feet of the old estate house would most certainly be accounting and business suites.

A halcyon inpatient facility -- there was no chipped paint, and the artwork illustrated nearly cliché Texas landscapes, custom-framed in flat blue hardwood. Two sea-foam green, cushioned chairs in each inpatient room converted into sleepers, enticing a spouse or child to nap when the patient was lost in stillness. The care center ran with all the conveniences of a four-star hotel, down to the quiet rollers on the meal carts.

Mostly though, inpatient care provided a chance for centralized materials and a pharmacy for when homecare nurses struggled to settle a patient. Once a skin-and-bones man yelped for two hours, through triple doses of *Xanax* and morphine, like a dog caught in a radio-electronic fence. After coercing his sister to trust he was not acting -- denial reared often as vagary in the elderly – the homecare nurses brought him in.

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Almost all benefactors want to *see* the results of their hard-raised donations. They do not want their money lost in the intangibles of a cause. Even for *The Hospice* benefactors, giving money had to result in the production of "things," from custom-made teak benches to non-denominational prayer gardens and replicas of royal English buildings. While extraordinary creature comforts from benefactors are certainly all good, they may mislead the community about the essence of hospice.

The comforts of *inpatient* care are provided to only twenty percent of the patients. The banner work of hospice takes place hither -- in a bedroom, at home, on flowered, polyester sheets -- or in a living room rearranged to house our one pink elephant that does receive insurance reimbursement: a rented, electric bed that raises and lowers with precision and a polypropylene mattress that *breathes* as it rocks a quiet patient from left to right and back again.

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Downhill from the inpatient facility, the outpatient nurses' trailer sat yards away from a winding bayou edged with a concrete embankment built by the city in effort to provide flood control during semitropical rains. Three times a year give or take, I learned, bayou water would forge across the grass and beneath the cinderblocks that raised the floor of the trailer five steps higher than the marshy land. Within the first hour of a storm, the nurses' cars would sit hip deep in brown water that climbed and amassed in circles. The trailer stayed put, but black ants and fire ants came into the rooms like urbanites exiting trains. Forced out of their hills as the floodwater passed through the crawlspace beneath us, in they came, onto desks, tables and counters, into cardboard boxes of medical supplies, up through the sink drains and down the walls. They disappeared in the speckled, industrial carpet. But true to form, Troy, from Maintenance and Supplies, always came down from the main building in his thigh-high waders with an insecticide canister the size of a bowling bag. He sprayed us clean of ants while calmly and generously sharing aphorisms like, *red or black, no such thang as a good ant*, or with extraordinary chivalry, *I take good care of my ladies.*

The outpatient nurses were secondary to the edifice as an enterprise. Our work took place hither. We were stationed downhill in a boggy trailer. When out in the city, we worked judiciously with materials and drugs that lay in the trunks of our cars. Whereas most families respected our utility, for those upon the hill where things were central and meaningful, we were just too plain in our bearing. Even for Troy. Once he said pensively, *not worth a hill of beans to fix yourself up in your line of work, but I bet you look good when you go out.*

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Weekend homecare required I drive my blue Honda through rush hour in one hundred degree heat, June through September, and through semitropical rains in October and November while taking cellphone calls dispatched from the after-hours service. Every Friday at five p.m., I turned on my beeper and cellphone, propped one hundred alphabetized charts in a red milk crate on the passenger's seat of my car. I folded a city map into orderly eighths, moored it between the seat and the console for the emergency brake.

I replenished the *Rubbermaid* storage containers in my car trunk with medical supplies: intravenous fluid bags and tubing, adult and pediatric urinary catheters, *Chux* and adult diapers and shrouds, *Keri*

lotion and *Eucerin*, salves and bandages, splints, a sphygmomanometer, a suction pump, two fire engine red needle canisters, four boxes of disposable gloves, pink tape, clear tape and white hypoallergenic paper tape, and one gallon bottle of bleach.

The drug box had to be picked-up on Friday and locked in a cabinet each Monday. The drug box was a plastic tackle box with the letter *B* painted on it in cherry-red nail polish. It was stuffed with needles and push ports and alcohol wipes, red, blue and green capped test tubes, saline, *Heparin*, *Scopolamine, Ativan, Benadryl, Valium*, and unofficially, any bootleg morphine we could dreg from the day nurses' bottles. Night calls for crisis pain made the three-hour wait for pharmaceutical deliveries excruciating when Abe gave an order at midnight for morphine to alleviate cancer pain.

We knew this was bending the rules, but it was so much more humane than the law.

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The unofficial authority of the *American Palliative Care Assessors* backed our weekend homecare program for four registered nurses, but we always hired two. Janine and I navigated calls and home visits from Friday to Monday. We worked the city grid collectively, driving about separately within a forty-mile radius from downtown. When one of us was bogged down, we divided urgent calls between us, staying to the right along Highway 59, pinning the cellphone to one shoulder while logging scrambling notes on a yellow legal pad.

Sometimes, we lost track of each other. When too many hours passed without an update, as soon as one nurse was free, she touched down on the other at the house of a patient who was still going through the paces. We clocked several hundred miles on our odometers per car each weekend, fielding calls in daylight and headlights. We averaged three hours of sleep each night. There were nights when I hung up the phone with my chin trembling, nights when I cried for the patient and for myself as I washed my face awake and brushed my hair into a ponytail.

But every Monday morning there was Sally Kane yelling from the doorway of the doublewide “welcome home, my strongest nurses!" Sally would wait for us waving pink phone messages in the air like parade flags. She would follow right along with Janine and me as we headed numbly to the kitchenette in the back of the trailer for hot glazed doughnuts from *Krispy Kreme*. She would cheer us on, reading out praiseful voicemail to us that she had just retrieved.

Amid the administrators, only Sally understood where we had been.

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The Hospice nurses who were watered-down Buddhists used to say that one goes into hospice not because of where one has been, but because of where one is destined.

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In those two years, I never had any trouble with the police about the contents of my car trunk. Several times, policemen were at a patient's home because a male family member had gone violent during a sudden death. While on my way over to the house, a female family member had called the police because either she or I were suddenly the intended repository for this rage. When I arrived, the policemen met me in the street, escorted me past the sweating and drunk son who threw a hammer and a ladder and a bicycle at the sheet rock of the garage wall when the cop lead me up the driveway, through the house, and through my work and then back to the street. One man had a pistol. One man grabbed my arm and shoved me into the kitchen.

The cops pinned these two against the wall and then took them for walks.

Truly within range of homicidal fervor that was ultimately about unspeakable grief, the cops never found the daring to say to me "whatcha got there?" upon seeing the narcotics in my box.

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Days before Suzanne was put under the morphine, she was agitated beyond circumstance with her hair salon, *La Tressisima*, extraordinarily so, for charging her forty-seven dollars for a designer haircut. Her reasoning went like this: she had been a regular customer for six years, since the day they opened their mod, steel doors; she had brought the salon business by parading the art of their first-chair coiffeur, Margie, out and about Bay Town, Deer Park and Clear Lake. Everyone knew from Suzanne's conversations that Margie worked half the week at *La Tressisima* and half the week in television cosmetology as the stylist for Ricki Lake.

Suzanne's reasoning ended in her having a snide conversation with herself:

> *Q: Margie overlooked that suddenly I have chemotherapy fuzz for hair?*
> *A: That cut should have been at most eighteen-fifty for a trim.*

The day after Suzanne died, the salon gave her husband a free haircut out of sympathy for his loss. At dawn, the morning of her funeral, *La Tressisima* burned to cinders.

When a hospice nurse hears this story, she believes it.

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Winifred answered the door to the one bedroom senior apartment on the twelfth floor of the northwest high-rise. She said with lovely, Jamaican ease, "hallo dare," then closed the door behind me. The noon light through the semi-sheer drapes crawled along the living room couch, moving the shadow of jade leaves on the sill across its cushions. Family photos in oval frames with ball-feet preened on skirted end tables and through the glass of a curio cabinet. Two white envelopes leaned against a table lamp. Otherwise, all was notably still.

At eighty-six, Evelyn Holcombe was dwindling. Winifred, a veteran nurse's aide, had called me to say "Evelyn has not been a-wake for a wholeday." In the bedroom, Evelyn was poised upon four white pillows on the left side of her king bed. Her round face was still complete but white as bone, framed by wooly gray hair. Neither strained nor blue, Evelyn was a pearl breathing low and slow, ten breaths per minute. I strained to hear her from the bedroom door. Near the bed, a wingback chair sat askew. A hot morning sky bent in through the open window. A white heat fought with the transit from the air-conditioner slowly tufting the curtains. Two pink towels were spread on a card table where Winifred had arranged diapers and washcloths, three snap-front nighties, lotion and a purple dome of talc that smelled like fruit drink.

Winifred looked at me. Reading my face, she said, "yes we are very close."

That morning when Win had washed her up, a stream of mucous rolled out from Evelyn's mouth. Win knew what this meant, so she had already called Evelyn's son to come from Dallas. From the living room, I called Abe, who prescribed *Scopalomine* to decrease lung secretions. We swabbed Evelyn with a warm, wrung cloth, and I stayed a medicine patch on the pappy underside of her arm. Win washed the basin, folded and

tidied the wet cloths in the bathroom sink before taking her due in the wingback chair.

Evelyn seemed snug and composed. The curtains were sufficiently twisted into stillness. The *scope* patch was kicking in. Win spoke to Evelyn teasingly about the impish eyes and polished smiles of kids in the picture frames who, "it was clear as this fine Sunday to see," played both sides of the fence with their grandmother.

Win turned to me. She said, “we are high," nodding to the open window, "to let her soul get free.”

At noon on the twelfth floor of a high-rise in Houston, on a Sunday, we had every indication that Evelyn would actually die in peace, when a woman's voice began to keen a ballad about evergreen trees. The clean, puncturing notes of this popular soprano milled in through the window.

I walked right out of the bedroom. Even easy deaths were *never* like this.

From the living room balcony, I could see a bus parked alongside Harrison Park, a landmark city green. Workers assembled a stage to the left of the fountain, a three-story "spill" down a wall of black marble. When squarely facing the water-wall from the ground, one takes on the thought it is an office building under deluge. There had to be an explanation for the singing. Speakers and amplifiers amassed in the grass near the bus, but where was the singer?

“A stranger thing Ah have never seen" Winifred called out from her chair, amused, and Evelyn was changing. She took long inhalations and fast exhalations. Spittle caught in her lips. Her fingers mottled, and her eyes grew sallow, blue rings. The singing continued, this time of a song about love and luck, and within these three minutes, Evelyn stopped.

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At six o'clock, *NEWS 2 Houston* featured the singer who gave a Sunday afternoon benefit concert for *AIDS* research at the water-wall. When I heard the music play from the television, I felt Evelyn again, alone at eighty-six, freed not by any measure of money or things, but by the happenstance of a voice singing laudably to the reaches of twelve floors, intangibly, her art for human charity.

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Notes on a Nurse's Narrative

"Hospice and the Intangible Wonders of Being" is one essay from a series on being a nurse. Since 2001, I have encountered a curious bandying of words, a struggle, concerning their reception.

"Signs of Waking," the first essay from this series arrived in print, gratefully, in the *Northwest Review* (volume 42, issue 3, 2004). On the cover of the journal, the editor (John Witte) dubbed the essay a "healing and story" piece. I liked this capsule very much though the essay still seemed to me to be more about trajectories of understanding than either healing or story *per se* -- even though I agree with accepted notions on grief processes and narrative, namely, that sense-making is a conceptual healing. For two years prior to its publication, editors seemed to spar with the nurse-narrator, contact me about their deliberation, and then decline the essay for print.

It seemed they had found her to be trouble. How strange it was to me to find they had found her to be disruptive to what a nurse was supposed to sound like, how a nurse was supposed to think and make meaning -- so much so that I sense she had been read as "pathology." This reception was a surprise, a reading far beyond my authorial intentions for her to bear normative grief and tell experiential truths.

Several years later, I have come to accept the trouble with her in the spirit that was true the summer I was eight reading a book called *The Trouble with Jenny's Ear* about a girl who had super-exceptional hearing and so had to take the bad with the good. "She takes her knocks," my mother would say, and so does the nurse narrator in these essays. In "Signs of Waking," she closes a complicated weave of memories and redefines her grief in order to stand up again. I suppose in some circles this is healing. I see her as one who can never fully walk away from grief with all the traumatic stress symptoms that happen after a great loss, just as I imagine those who were able to exit Plato's cave to manifest as well.

Reconstructing a shattered life narrative is tough business, and that is what I try to do in these essays, each of them sense-seeking from end to end. Thank god for the sympathetic editors who have welcomed her tales, the likes of which do not often get valorized in print.

The sanctioned narratives of a dominant culture are powerful influences, even if only unconscious ones, that go so far as to warn those

who live outside the culture that a critical narrator may be unreliable and thus may be, herself, pathological.

And god help her when the culture is medical.

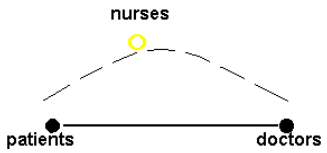
After the publication of "Signs of Waking," I had tapped on the door of several health care journals, figuratively and optimistically – sent letters to editors in various medical communities who might have had interest in this nurse narrator. Narrative medicine had appeared in the pedagogical missions of major American medical schools well long enough that I thought medical editors might find her life central and relevant to the "medicine & humanism" conversation. Several weeks in, I received a formal (distant and formulaic) rejection from the *Journal of the American Medical Association*.

Many, many months in, I received an urgent email from Danielle Ofri, the physician editor at *Bellevue Literary Review*. She assigned several pages of "revision bullets" including idea changes -- of the type, *on page eleven, you can't say 'that' about doctors* -- due back to her within three days, even upon telling her that my writing was being wheeled into my new home by movers, and I was on my way out of town for a family wedding.

She wanted something more from me than smoothing. I remember this still. She was offended by the nurse-narrator who had no stewardship to the physician. She wanted some sort of obedience from my narrator to her own version of what I should have written – especially when it came to my narrator's comments about doctors. "Doctors," I wrote:

> have integrated senses of their importance, their authority, wrapped in the ideologies of doctoring. In medical school, they are trained in their confidence. Some of this is necessary; who would trust the advice of a doctor who lacked self-assurance? Some of this is insolence, a consequence of fragile egos, and a belief in the deserved status of a privileged class.

I defended my narrator's trajectory this way:



A few days later, after changing wedding plans so as to work through the mandated changes, the "editorial board" at *Bellevue Literary Review* rejected the essay.

The fiction writer James Robison once said to me that when someone tells you the way they would have written your story, you might take the comment as the highest form of flattery – when a reader begins to write her own version of your piece, then you have done well.

By the time I sent the essay to the *Northwest Review*, I had cut the "doctor" paragraph entirely. Since the narrator's rendering of meaning was inscribed with a truth-aim about "being a nurse," the biting tone of this passage seemed to "wrong" my narrative goal. I decided the narration should engage its lens responsibly on the nurses' arc with little mind and little emotion for doctoring or doctors.

Somewhere in time between *Bellevue Literary Review* and the *Northwest Review*, Cullen Murphy, the managing editor of *The Atlantic Monthly*, sent me a personal rejection note stating that he was so interested in the writing of this essay that he sent it to his sister, a nurse, who verified for him that nurses *do* feel *this* way. However, he wrote, he had to reject the piece on account of his "medical" file being stuffed beyond what he could print for some time.

I was happy with this response for a while -- to think, even Cullen Murphy knows a nurse.

Where I come from, one could have trusted one's gut on this. Chances were likely enough that the fathers on my block would have carried on about it. Mr. Cosgrove would have said, "*Faith and bejesus, Mary, a Cull-en Murp-hy would cer-tain-ly have a nurse in the family,*" and then he and Mr. Boylan would have softly cuffed my noggin. Then they would have taken me on a trip to the strip mall so they could bet on the ponies.

It's been all this schooling. It's taken me a few years to see that if Cullen Murphy really wanted to, he *could* have taken the essay.

Surely, I had learned enough.

Before finding *DoubleTake / Points of Entry*, I sent "Hospice and the Intangible Wonders of Being" to the *American Journal of Nursing*. Weeks later, Tom Schwarz, the editorial director and number two person at the magazine, called me on the phone. He told me that he does not

normally call the writers who submit work but that the essay I sent him was beautifully written, and he was struck.

"You are in the top 2%," he said.

"Nurses can't write like this," he said.

My hands were shaking; I was so elated.

"But you can't make the *Queen Mary* make a right angle turn," he said.

So he too rejected the essay.

"But *you* can!" I pleaded, and he convinced me very graciously that not even he could do so – that the only place in the magazine for a nurse's experiential prose was in their column called "reflections" and this had a tight word limit utilized mostly for inspirational verse.

We talked a bit about narrative medicine. We talked about the need for writing from experience in nursing curriculum, if only to decrease nursing burnout. We talked about the need for nurses to be active participants in the professional conversations in the medical humanities.

I talked about the need for women to write their experiences and since 93% of nurses are women,

"Uh-hum," he said,

there was a gender issue that was perpetuating the silence of women whose identities were betrothed to serving others. I had nothing to lose. We got off the phone here.

So who can make the *Queen Mary* turn?

The trouble with my narrator is about industry. The machinations of corporate publishing are so huge and heavy that an editor cannot maneuver against the momentum. In "Hospice and the Intangible Wonders of Being," I critique why the hospice industry spends money on things. It occurs to me now that an industry that signifies a personal nature *out of ideological conviction* is a highly unusual one. In health care, the signification means *caring*. In most circumstances, this signification is not a circumspect one. In my thirteen years as a nurse, all but one nurse manager felt that the bottom line of our work with patients not only had to communicate caring but had to be done because one really does cares. As an industry, hospice deserves some credit for aiming to

adhere to such a personal, human principle, notwithstanding how in corporate dailiness signifying ideology can be tactless.

The *impersonal* nature of corporate publishing steers journals like the *American Journal of Nursing*. *Ipso facto* goes the reasoning at the *American Journal of Nursing* – by the very fact that a nursing journal precludes narrative from its scope since it is not empirical, reifies that empiricism is of sole value to the profession -- even though we know the intangible nature of caring, even though nurses are good storytellers with each other, even though there is now data on the correlation between narrative and healing, even though the matter of the soul is the sea and the body is sixty percent water.

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