

MY MOTHER, MY STORY

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Abstract This piece returns to the writer’s memoir essays about her mother’s chronic lung disease to examine the relationship between the act of caregiving and the act of writing. In arguing for important differences between the clinical, healing imperatives of narrative medicine and the primacy for the writer of self-reflection, personal need and career, the essay demonstrates how writing remains in many ways at odds with the obligations and the hopes of caregiving. At the same time, the essay argues that writing her mother’s stories of illness holds the potential for both honor and mutuality—and can, in fact, constitute a form of caregiving.

Keywords medical humanities · personal essay · caregiving · narrative medicine · end-of-life

For the past five years, I have been “following” my mother’s chronic obstructive pulmonary disease—not only as a daughter but also as a writer. In April of 2008, when my mother’s pulmonologist first prescribed a home oxygen concentrator and a portable oxygen system, the limits of my mother’s aging body suddenly became—at least to me—frighteningly audible. And I began writing:

From every room in her apartment I can hear my mother’s breath. The steady hiss of force—not her own—drawing from tubes and canisters in the interstices of television sound. Clear plastic is clipped in her nostrils, crossing her face; green tubing curls and uncurls in her wake. She turns and whips the knotting line behind her, untangling and clearing, making her careful way from the hall to the kitchen. She is feeding on oxygen.

I remember how her breath used to quicken in the summer sun—how she inhaled in even gulps between sets of tennis, balancing casually on the handle of her racquet. What required air she could easily do: take the green lawn with the mower in long, circling rows, leaving stacked clippings drying behind her in the heat; rake the heavy leaves to the curb at the chill, wet end of autumn; paint the kitchen walls; unload groceries from the car, lug bags up the sidewalk from the garage, jam open the screen door with one

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crooked arm while she balanced a sack of canned soup and frozen vegetables and a half-gallon of skim milk with the other. She'd wait for my little sister to climb the back steps one by one and then steer her through the spring door that strained against her own back: *Scoot!*

Her oxygen is delivered now, pumped into a green drum half my height in the front hall. She fills a canister when she leaves the house and straps it to her back, counting the minutes. Breathing has become work. (Jacobson 2011b, 117-118)

I have come to the act—the obligation—of caregiving from hundreds of miles away: from New York, where I now live, to Chicago, where my mother has spent her entire life. If *present-ness* lies at the essential heart of “caregiving,” distance surely poses considerable obstacles, and although I try to visit regularly and to help, especially when my mother’s needs are great, I am aware that others’ commitments to caregiving are vastly more quotidian and intimate. Yet I have also made my own commitment: to be with my mother as a writer in what I know are her last years. In this commitment to the present tense, the essays that I have been writing aim to break from the single, retrospective point of view that is conventional in memoir—to be present with language at what we call the “end of life” while it is still *life*.

Writing so steadily in the present raises a number of challenging questions about narrative—and about narrators. Is it possible to be “narratively present” when it is not possible to be physically present? Can one provide a form of care by offering narrative? Narrative promises both to bridge the isolating divide between writer and subject and to give unifying shape to the raw shards of experience; as the critic of autobiography Paul John Eakin has put it, narrative can “bring the chaos of history to heel” (1992, 160). Yet we know that this promise needs to be shadowed by caution. Jodi Halpern writes of an Asperger’s patient’s sense of humiliation in reading his psychotherapist’s published article about him, highlighting the “potentially reductive” status of narrative about someone else’s life (2011, 660, 661). And Susan Sontag insists that there are actually cognitive boundaries—beyond metaphor—between “the kingdom of the well” and “the kingdom of the sick” (2001, 3), as well as between those who hope to grasp traumas like war through visual image and through language and those who have directly experienced them (2003, 126).

Where do these doubts leave those of us—like me—who “follow” in the wake of others’ illness, making narrative? Where is the boundary between the responsible status of witness and the potential for exploitation and violation?

What am I doing when I write about someone else’s illness, about someone else’s body?

For advocates of narrative medicine—professional caregivers, caregiving professionals—a story is, inevitably, bound up with a set of clinical imperatives. Kathryn Montgomery Hunter and others have observed that medicine proceeds through a chain of narratives that reach from the patient’s initial reporting of her condition through the case history, the case presentation, the case report, and, ultimately, from the physician back to the patient (1993, 57). In arguing, in turn, for the primacy of listening well to a patient’s story—“to make room for its teller” (2004, 863)—Rita Charon argues for narrative medicine’s ability to return the chaotic, ill world to us in whole-making, healing “sequential stories” (2001, 1900).

Like her hopes for narrative, Charon’s language here is clinical. Challenging hierarchy—“bridging the divides that separate physicians from patients, themselves, colleagues, and society” (2001, 1897)—the goal of “narrative competence” in medicine (2004, 862) is to create what Charon calls “a therapeutic alliance” (2001, 1899).

Yet it is not at all clear that this ideal of “alliance”—of collaboration—is one that the writer seeks, or even ought to seek, to emulate. It is not, it seems to me, a given that the authority to

author their subject matter is authority that writers ought to be prepared to cede. Nor does it follow that the writer owes an obligation to the well-being, much less to the healing, of her subject.

The hunger for a creative legacy; the power to claim, rather than to share, authorship—these are in many ways different hopes for narrative than the therapeutic hopes of narrative medicine. This difference is illuminated in disturbing ways in Bennett Miller's 2005 film *Capote*, in which Truman Capote (played by Philip Seymour Hoffman) has bought himself writing time by helping convicted murderer Perry Smith with legal support for his death row appeals. But when Capote has finally finished the manuscript of his "nonfiction novel" *In Cold Blood*, in which Perry figures as one of the two central characters, he decisively—cold-bloodedly—ends their relationship: "This is my work, Perry; I'm working." Capote cuts Perry off and turns and walks away, free, down the prison corridor. In his *New Yorker* review, David Denby highlights the film's illumination of the power disparity between the writer and his subject, and the writer's strategic skirting of ethical boundaries, calling *Capote* "the most intelligent, detailed, and absorbing film ever made about a writer's working method and character—in this case, a mixed quiver of strength, guile, malice, and mendacity" (2005).

Given medicine's unarguably ethical obligations to the patient, it makes sense that negotiating the rhetorical boundary between patient and doctor has emphasized the language of "informed consent" and the "disclosure statement." As Katie Watson, the editor of *Atrium*, at Northwestern University's Medical Humanities and Bioethics Program, asserts, "clinicians who want to publish case reports are not just disinterested purveyors of knowledge. They are paid in the academic currency of prestige and career advancement" (2011, 658). No literary journal would be likely to require writers to provide informed consent documentation. But when *Atrium* published one of my essays about my mother, Watson insisted on drafting a "confidentiality and disclosure" statement for it: "The author understands this to be her story as well, and therefore believes permission is not required" (Jacobson 2011a, 6). Indeed, my essay opens with an appreciative accounting of my mother's daily, slogging battle to sustain her own physical equilibrium: "My mother can go on every day, even when she feels tired or chilled or discouraged . . . but she cannot beat back completely the respiratory infections that keep recurring and turning into pneumonia, more serious each time" (6). But in the essay's conclusion my own emotional fatigue takes precedence over my mother's feelings:

I try not to count the minutes as she showers and decides what to wear; as she pulls up her socks with the long shoehorn on which she depends because of her arthritis; as she puts on her plastic mask and inhales medicated mist; as she makes breakfast and eats it; as she puts all the dishes in the sink and she wipes her placemat; as she fills her oxygen tank and she grabs the stamped mail; as she braces for her first cautious breath of chill, hurting air. My mother is no longer strong enough to clean her apartment, and she claims that she doesn't have the time to look for help or the money to pay for it. I try to convince her otherwise—she has plenty of both!—first reassuring and then squabbling with her, until both of us are weary although nothing is settled; until it's hard to remember love. (6)

After two and a half years of writing about my mother's progressing illness—of filling notebooks with my own observations as my sister, my wife and I pressured her to leave the suburban Chicago apartment and garden that she loved and move to a facility where she would have the community and the care that we believed she needed—I finally shared five published essays from this project with my mother. I felt anxious about the possibility that in reading

these personal and revealing essays my mother would feel hurt and even—I must also admit, my most gnawing concern—ask me to stop writing about her. But I had been keeping the project a secret from my mother even after she had inquired repeatedly what I was writing about, since my previous book, a family memoir about growing up in the suburbs (Jacobson 2007) had come out—even after she had pointedly said more than once, “I hope that you’re not writing again about *me!*”

To my surprise and relief, my mother was not uncomfortable with the work. She was primarily disturbed by the many places in the essays where she felt characterized as more needy, less self-sufficient, than she actually feels. “You shouldn’t call this a ‘retirement home,’” she corrected me, looking up suddenly from the pages that she had been slowly reading, “This is ‘independent living.’” And my mother had one more point to make: that the texture of sadness in these essays seemed to her to belong to me, as I witnessed her aging, rather than to her; that in fact my essays seemed to be more *my* story than hers.

Perhaps I should not have been surprised by that insight. Writing about his grandmother and about his patients, the physician-poet Rafael Campo acknowledges how the centrality of his own need shapes the writer’s presence and the writer’s work: “The only way we can defy our own mortality is through acts of the imagination” (2011, 22). My own experience amply demonstrates how the narrator’s voice can have a possessiveness, a territoriality, that takes primacy over obligation to its subject, even when illness renders that subject tentative and vulnerable—and even when that subject is another writer.

Almost fifteen years ago, my friend Richard McCann wrote hauntingly about the emotional uncertainties that shadowed his therapeutic medical narrative of being a liver transplant recipient. “Here is what happened,” he wrote,

I was cut apart.

The liver of a dead person was placed inside me so I might live again. . . .

But who was I afterward? (1999, 188)

Primary though (obviously) Richard’s own narrative of his experience was, it also spawned other stories: “making room,” to adapt Charon’s words, for other tellers. As Richard’s confused and overwhelmed caregiver, it was about my own feelings that I wrote in a “Piece of My Mind” column in the *Journal of the American Medical Association*:

The nurse changing Richard’s dressing uncovers the skid marks of death, slowing to a faint conclusion. . . . I can feel myself, already, retreating from the dizzy edge where my love for this man has taken me and made me an unready witness to such profound disruption. And once more I am ashamed, for I can hardly wait to leave his hospital room. (Jacobson 1998, 906).

Surely most of us—caregivers *and* writers—who bring the power of narrative into the hospital and the sickroom share the same commitments to optimism and decency, to realizing fully our own humanity. And at the familiar fault line of the body, a great deal about what it means to be human is vividly revealed. The physician (and editor of the *Bellevue Literary Review*) Danielle Ofri has written in the *New York Times* about her own struggle over whether to be truthful with a patient about her dark prognosis. Ofri concludes that her initial decision not to share that painful information “reveals more about the diagnosis of being human than anything else” (2012, A27).

Yet narrative is not, I believe, freighted with precisely the same questions and obligations for writers and for caregivers. Both writers and caregivers clearly learn about themselves and

their own feelings—and grow—in their work and in the self-reflective work of narrative. I have learned from the work of writing, of making narrative, that language itself marks a boundary between my mother and me:

“I’m fine,” my mother tells me when I phone from home in New York. . . . “I’ve got plenty to do today, more than enough to keep me busy.” Today, when the cold is not so bad, she is going grocery shopping. She’ll see what’s on sale, what kind of fruit is cheap in the Chicago markets in the dead of winter, what brand of frozen green peas has been marked down at the A&P—the narrowing economy of going on. . . .

“That’s the road we travel,” a man tells a young television interviewer after a member of the chorus in which he sings in Massachusetts—men and women in their seventies and eighties and nineties—dies the night before the concert for which they’ve been preparing for months. My mother is traveling that road too, moving at her own pace, saying what she needs to say. Her way is the way of doing until there’s no more to be done, not the way—my way—of words. (Jacobson 2013a, 61–62)

Rita Charon asserts that in the practice of medicine physicians “cultivate private affirmation of human strength, acceptance of human weakness, familiarity with suffering, and a capacity to forgive and be forgiven” (2001, 1899). But my own writing about my mother’s illness is not, really, meant to heal. We can hear in my mother’s own voice how she turned back to me the stories that I’d written: “My overall feeling,” she told me, recapping our half-hour conversation, “is that this is sad—and I don’t feel sad about it.” “So you feel like maybe I’m sadder than you are. . . . ?” I asked. “It looks like it, doesn’t it,” she replied. My mother recognized—before I did—that it is not simply her illness that I have been following in *Every Last Breath*, that the story I am telling in so many ways is my own.

I’m grateful to have come to this moment with my mother, relieved no longer to be concealing my work from her. Just the same, if we can recognize that the work is about sadness and love—*my* sadness and *my* love—my writing, like the heart, also remains a keeper of secrets. And that writing’s voice has its own imperatives, at least some of which remain at odds with the obligations and the hopes of caregiving:

Inside Chicago’s Shedd Aquarium are the sea’s most strange creatures, delicate and fierce. Barely flesh at all, jellyfish can trail tentacles as long as one hundred feet, can coast the ocean’s warm currents for miles, breathing symbiotically through algae if they enter deep zones where the oxygen supply is low; can sting and kill human beings. My mother is less than five feet tall, and she is carrying an oxygen tank that weighs four pounds. Arthritis has stiffened her body. She moves slowly, dangling plastic tubing through which we can hear her take wheezing breaths.

Take me, my sister and I know my mother will say if we tell her about the jellies exhibit, but it is too much for us to face—to drop her off at the handicapped entrance, to park the car and walk back in winter’s cold across the long, crowded lot—more than we are willing to do. The screaming kids, the fish-shaped French fries ground underfoot; the hard work of salvaging excitement, and of seeing her so changed. It will always be our secret how we let regret steer us past one of life’s small, late offerings, how we said no without saying a word; how we turned away from our mother without letting her know that we felt we had to. (Jacobson 2010)

And yet the writer's refusal of the caregiver's responsibility of selflessness is not by any means a refusal of caring, or even of caregiving. If, for example, storytelling enables the writer's miraculous transcendence of his own mortality, Campo argues that it also enables the writer to share that gift with his subject: "the poem written by the resident, who failed to resuscitate her patient in the hospital, perhaps has done her an even greater service, by immortalizing her" (2011 22). And if the potential for violation surrounds with warnings the act of writing about another person's illness and body, the imperative of treating another human being's stories with respect and tenderness holds the promise, I believe, of another kind of caregiving.

In her thoughtful comments about my essays about my mother, she gave me permission, I also believe, to take her stories and to make them mine. We can see revealed in that gesture the mutuality not only of caregiving—a mother's generous recognition of what her daughter needed from her, and of what she could still, near the end of her life, give her daughter—but, also, of storytelling. Two summers ago I made the decision to conclude my cycle of essays with my mother's return in her eighties to gardening, rather than to continue writing until the end of her life. As my mother's physical, and then mental, decline began to take swifter shape, I realized that narrating it in public felt voyeuristic. I had the sense that the stories that my mother had given me—and the stories that I had made from what she gave me—were coming to an end, and that recognizing that conclusion was an obligation of respect, and of love, that I owed my mother.

To care for my mother's stories became at that moment, I think, one of the deepest forms of caregiving I was capable of providing my mother from halfway across the continent. That caregiving remains intimately rooted in who I am—a writer—and in what writing has enabled me to lovingly acknowledge and to preserve about my mother. And it has revealed more about the wise mysteries of the present tense than I ever could have guessed when I began writing about my mother five years ago:

Even today, when her movement must be frugal, her breath slowed, my mother seeks out her garden in the morning coolness. She carries a trowel, and the plastic bags from the grocery store that she's saved to collect weeds and dead flowers. She pauses when she comes to the end of the path, assessing what has grown in the sun since the day before, and slowly circles her plantings. She disconnects the oxygen tubing when I ask to take a picture; that is not who she wants to be, especially here, where she has renewed in her last years her refusal of loss. She does not think about dying, she tells me when I ask, nor does she think ahead many mornings beyond this one. My mother has no interest in death's deals, in . . . sacrificing even for a moment the gift of *now* that she had been granted.

She gently cups a low, fresh flower, something that wasn't open last time she worked in this modest garden. Isn't this what we all dream of, the promise of forever starting over, the human means of making new life and—even—beauty still at hand? (Jacobson 2013b, 41-42)

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