A University of California author or department has made this article openly available. Thanks to the Academic Senate's Open Access Policy, a great many UC-authored scholarly publications will now be freely available on this site.

Let us know how this access is important for you. We want to hear your story! http://escholarship.org/reader_feedback.html



Peer Reviewed

Title:

Always a surprise, even a wonder: poetry and commentary.

Journal Issue:

The Journal of medical humanities, 28(2)

Author:

Haddad, Amy Pucciani, Donna Shapiro, Johanna Shafer, Audrey

Publication Date:

June 1, 2007

Series:

UC Irvine Previously Published Works

Permalink:

http://escholarship.org/uc/item/02m3623f

Keywords:

Grief, Humans, Medicine in Literature, Poetry as Topic, Terminal Care, Terminally III

Local Identifier:

17464450

Copyright Information:



Always a Surprise, Even a Wonder: Poetry and Commentary

Amy Haddad · Donna Pucciani · Johanna Shapiro · **Audrey Shafer**

Published online: 27 April 2007

© Springer Science + Business Media, LLC 2007

Introduction

Life passages are rarely blinkered leaps into new territory with nary a backward glance. Rather, such journeys are marked by forward and backward glimpses, yearnings, side steps and ultimately transformations which are as dependent on the journeys themselves as on the starting and ending points. How we choose to mark such passages—to honor, respect, vilify, dissect, fight and accept them-is the stuff of lives lived, witnessed, held. It is the stuff of poetry.

The three educator-poets featured here lead us on their journeys of loss and discovery. Like good guides, each knows her terrain and points out not only vistas but also small yet telling details. Each also allows us moments to catch our breath between startling turns which leave us breathless with wonder. We are led into private spaces: bedrooms, nursing facilities, operating rooms. And further—into the privacy of passion and grief.

Just as we learn to cherish health and life through the experience of loss, these poets teach us that the experiences of sorrow and pain can be spun into lyric images aching with

A. Haddad

School of Pharmacy and Health Professions, Center for Health Policy and Ethics, Creighton University Medical Center e-mail: AmyHaddad@creighton.edu

D Pucciani

25W707 Flint Creek, Wheaton, IL 60187, USA

e-mail: dpucciani@yahoo.com

J. Shapiro

Program in Medical Humanities and Arts, Department of Family Medicine, University of California Irvine School of Medicine, 101 City Dr. South, Route 81, Building 200, Orange, CA 92868, USA

e-mail: jfshapir@uci.edu

A. Shafer (⊠)

Anesthesia 112A, VAPAHCS, 3801 Miranda Ave, Palo Alto, CA 94304, USA

e-mail: ashafer@stanford.edu



beauty. The movement of a repeatedly opening and closing hand in Haddad's poem, the touch of a father's hatbrim to a grown daughter's forehead in Pucciani's, the tiniest, horrifying Matryoshka doll in Shapiro's—all describe with poignant clarity what it means to be transformed. For if words translate emotion, turning primal screams into meaning, then poetry, with its choices of what is said and what is left unsaid, honors both the word and the scream. We, as readers, benefit from the poet's refusal to turn aside. We are transformed by the embrace of the surprises of life, the sifting through the shadows of loss, and the wonder that we all possess such a capacity to love.

Flexion/Extension

The hospital bed fills the small room forcing the dresser out in the hallway. I sit sewing buttons on clothes I never wear, hate mending but my hands need to be busy, a mindless task while I watch my Dad. The bed, a huge metallic insect stuck on the pink hooked rugs in my parents' room, holds my father up so he can breathe. I watch him out of the corner of my eye, his chest rises erratically and falls. He stares up at the ceiling, slowly opens then closes his left hand, over and over. Cupping my hand over his soft hand that labored in music and contracts. "Dad? You okay?" He nods and as soon as I take up my sewing, he picks up the rhythm again, open, close, open, close. I have seen other patients do this sometimes gathering up the sheet as they do, absently not urgently, collecting, releasing.

-Amy Haddad

Commentary on Flexion/Extension by Amy Haddad

This poem rests in the narrow space between my father's living and dying and the parts of me who are daughter and nurse. Because my father died of congestive heart failure, his dying was slow, over many months, with plateaus when he stabilized for a while and times when he would be critically ill. After many trips to intensive care and long recovery periods in a skilled nursing facility, he told us he never wanted to go back to the hospital again. Hence, the next time he went into cardiac failure, we knew he would probably die at home. My mother, brother and I talked about hospice, but we never discussed this with my dad. I



learned how wonderful the support of hospice can be, yet the process still requires a great deal from family members. The invasion of the medical into the familiarity of my parents' bedroom, the most private of spaces in my childhood home, was unsettling. The bedroom was now occupied by foreign, ugly equipment and odd noises from the oxygen concentrator. My mother had to cope with strangers like the respiratory therapist and home health aide. Not knowing whether they were guests or helpers, my mother brewed coffee and warmed sweet rolls for them.

I often sat with my dad so my mom could take a break, go to the store or have her hair done. As he got closer to dying, the sitting was often just that—being present, not really doing anything for him. It was hard for the nurse in me just to sit there. What struck me many times as I sat beside his bed, watching him, was all the letting go and holding on that comes when someone you love is dying. At one point, when we were alone, he said, "I am going to miss you." I had not even thought about how he was losing everyone and everything he loved. I noticed the small gesture of opening and closing his hand and realized I had seen it many times before in clinical practice. The nurse in me responded to the meaning of this gesture, the daughter in me wanted to hold on a little longer.

My father, a proud and private man, might not have approved of my sharing these reflections on why I wrote this poem.

I hope he would like the poem.

Daddy-Shadow, Daddy-Shell

He dozes in nursing home dark, shadow among shadows.

Daddy in little pieces, see-through man, shrunken, curled up in the pink vinyl reclining chair,

sunk in the timeless tide of sleep as a broken seashell on a deserted beach

no longer desires the crash of the wave or the salty, foam-breathed embrace of the deep,

but only the ebb, the stasis of wet-dragged sand bidding farewell to the sea.

He stirs, an organism forgotten by himself, unfolding each wrinkle of skin, each brittle finger,

knowing there is someone in the room, a familiar voice or two above him in the dark, waiting.

Desiccated, he tries to drag himself, crumbling, translucent, into the unwelcome brilliance of day.

-Donna Pucciani



Saving His Hat

I'd thought it would be easy, the last sorting. After all, he wouldn't be at my elbow in the wheelchair, insisting: Save this! Keep that! That shirt's a Brooks Brothers!

Each move was another grand threshing and winnowing into places where possessions meant nothing, a three-piece suit no longer needed in the bingo-and-rosary landscape.

Now to finish the taxes, bills, thank-you notes. The final gleaning, where sadness promises relief. The gladsome disposal of bleach-ridden sheets, his dozen flashlights to fight hallucinations,

the transistor radio grimed and static, sticky shavers with dull blades—all crammed into a black plastic bag hauled out to the curb. Let it go.

The nursing home has forgotten to return a bedside lamp, his favorite quilt, a box of incidentals. I think I'll die of exhaustion

as the social worker leads me down the pink linoleum hall past invisible wheelchairs, audible groans, saying, "Yes, we lost our little Frank,"

and I struggle not to bend in two as I hold his tweed hat, touch my forehead to the brim, and smell the weight of his aftershave like a wave of cinnamon in my throat.

-Donna Pucciani

Mysteries

We look at pictures of thinning bones, apparently mine.

The doctor uses words like "putting off the inevitable," "consult a specialist," "you're doing all the right things."



The doctor is kindly, and speaks the truth. He respects the woman who disintegrates before his very eyes, having seen such things before. "Fractures." "Pain." Substance becomes ash, the solid ephemeral. He prefers the mystery of birth, ponders his own children's tiny limbs, having embraced them this morning before cereal and fruit.

I think of other mysteries: web-footed men beckoning from hedgerows, licorice allsorts coating the tongue black, elves, trolls, deserted villages, déjà vu, owls and banshees, dark wings flapping in a wood, half-remembered nursery rhymes, galaxies, a whistled piece of tune, a lock with no key, attic stairs, the missing ingredient in a pie, lost umbrellas, misplaced sunglasses, mice in the walls, black holes, a suitcase that won't open, the smell of smoke.

Puzzlement gathers itself for the final riddle. Abracadabra does not work.

No spells, no charms.

A trail of breadcrumbs vanishes like bone on a dexa-scan. Life is a little tune played backwards. I must learn to disappear gracefully.

-Donna Pucciani

Commentary on *Daddy-Shadow*, *Daddy-Shell*, *Saving His Hat*, and *Mysteries* by Donna Pucciani

I wrote *Daddy-Shadow, Daddy-Shell* 3 years before my father's death, when he was a nursing home resident close to my house in Illinois. I felt lucky he could be at such a facility as he confronted the ravages of Parkinson's disease. My husband and I are both full-time high school teachers, and after a 60-h workweek, with more papers to grade on the weekend as well as Peter's soccer coaching duties and games, we rather desperately garnered the time and energy to visit Dad every weekend.

After my mother's death in New Orleans, we had moved Dad to a senior citizens' apartment for a few years, but gradual immobility and incontinence made it impossible for him to continue there, and he reluctantly settled into the clean, bright place near us. He yearned for company but was hard-of-hearing and refused to wear his state-of-the-art hearing aid unless I was there to cajole him. The staff did not engage in that task each day;



his sense of isolation, partly self-induced, was heartbreaking to observe. His poor vision, affected by Parkinson's, prevented this brilliant man, with an M.A. in economics from Rutgers and a career which included vice presidency of a corporation in Manhattan, from reading. I still feel guilty about not being able to do it all: the bills, banking, correspondence and taxes; the neurologist, audiologist, and optometrist; new clothing and shoes as he lost more weight; unsuccessful efforts to have his meds administered on time; cheering him up and taking him out, though it became increasingly difficult for me to haul him and the wheelchair in and out of the car. And I was continually preoccupied by the fear of what would happen when we ran out of money, as Dad's savings were being rapidly depleted by the cost of care and medicine.

I remember fielding telephone calls from the nurses about his frequent falls, his reactions to medication, and other emergencies. But the worst stage of all was when he would emerge foggily from his hallucinations, not recognizing us, mumbling incoherently, floating in and out of his Parkinsonian dementia. Yet just a few months before his death, we were able to wheel him into the garden, sit in the sun, and talk about his favorite book, Thomas Mann's *The Magic Mountain*, set in the microcosm of a sanitorium. The image of Dad as a wispy shadow of his former self—an empty, fragile shell—became more and more haunting as we visited him weekly and observed his slow demise. Finally, he was moved upstairs to the Alzheimer's unit, which, with his sardonic wit, he had observed to be "the last stop."

Saving His Hat was written after my father's death in 2001. The news came the day we arrived in England to visit Peter's sister, having seen Dad just a week before. My last vision of him was propped up in his wheel chair in the hall near the nurses' station, gray and sagging, lost and alone. He vaguely knew us or, perhaps, not at all. We chatted with him for an hour, as we had many times before. I kissed him on the cheek and left, unaware that the endless visits were about to end.

The nuns and night staff at the nursing home talked to me over the phone long-distance and were a great comfort, having routinely checked on him and changed him at midnight, then found him dead at two a.m. They had gathered around, said some prayers and memories at his bedside. Dad and I had made funeral arrangements 2 years prior. He had chosen a quote from his favorite poem, *Thanatopsis*, for his memorial card but requested no service. He merely asked that we go out for a quiet meal to his favorite Italian restaurant, Clara's, a little storefront eatery where, on the good days, we used to have pasta and Chianti together. (The head nurse had ridiculed his penchant for food and wine, thinking it pretentious, probably unaware of his southern Italian peasant roots. I hope Dad never noticed.)

When we returned from England 4 weeks later, I thought all the tears of sadness and relief had been shed, but I was unprepared for my last visit to the nursing home to gather his belongings. I have since read several books by health care professionals on death and dying and realize that Dad on some level probably chose to die when he did with us across the Atlantic and his not being a "bother," never one to make a fuss. His vulnerability was always reticent yet palpable. And now, his death, without closure.

About *Mysteries*: after negotiating the final years of my parents, I started to become aware of my own physical and psychological needs with both relief and chagrin. My doctors had been tracking my bone density, which was declining precipitously and bordered on osteoporosis, though I was only in my fifties. I became aware of how one can look perfectly healthy on the outside but actually be disappearing on the inside: Dad's brain, my



skeleton. It was quirky and odd, yet the scans showed the unequivocal truth. My dedicated family doctor, Dr. Saguil, said we are all just putting off the inevitable, but Dad's favorite poet, William Cullen Bryant, would have added these words:

So live, that when thy summons comes to join The innumerable caravan, which moves To that mysterious realm, where each shall take His chamber in the silent halls of death, Thou go not, like the quarry-slave at night, ...but, sustained and soothed By an unfaltering trust, approach thy grave Like one who wraps the drapery of his couch About him, and lies down to pleasant dreams.

Bryant, WC. *Thanatopsis*. In *Yale Book of American Verse*, ed. TR. Lounsbury (New Haven: Yale University Press, 1912).

Russian Dolls

As a child, not yet a woman
I loved those Russian dolls-within-dolls
The smooth, colorful, varnished surfaces
of that red-cheeked, flowering babushka
and (as I conceived it) her many daughters
some happy, some pensive
all safely tucked away inside the womb
of their mother.

But the one I liked best was the last one of all The littlest daughter the tiny baby I claimed as my own

Now once again
the magical dolls open up
to reveal their secrets
The scalpel carves neatly through the
superficial flesh
plunges deeper into the abdominal cavity
then penetrates the core of womanhood itself—
Oh marvelous uterus—home to such beautiful babies!—
Still pure, still pure these dolls
greeting each opening with a
benignly smiling countenance



The knife keeps twisting into the innocuous fibroid resting securely within the uterine wall finally reaching the heterogeneous mass Of cells within

The tiniest doll of all Leers back at the astonished surgeon With malignant eyes

-Johanna Shapiro

Tarot Cards

All of a sudden in my life the news is never good We've found a mass It could be cancer You need surgery It is cancer It could be fatal Sorry, it is an orphan cancer No one knows much about it We think it is too big to just watch and wait We can try this approach But there's no proof it works You'll probably have recurrences Maybe more surgeries if you're lucky. We save radiation and chemo to the last because they're not all that effective.

I think of myself as a scientist I've been trained to believe in numbers, data, evidence But in their absence in a world of bad news I now read my fortune cookies with more care I pay attention



when friends dream
they see me healed and whole
I scan the papers
for improbable happy endings
And when my eighty-five year old mother
reads the tarot cards for me
and pronounces them
just beautiful, not a single
black card among them
I am consoled.

-Johanna Shapiro

Commentary on Russian Dolls and Tarot Cards by Johanna Shapiro

Becoming a patient often involves hard-to-categorize surprises which combine strange interplays of wonder and horror. When I was diagnosed with endometrial stromal sarcoma (ESS) in 2004, it was a surprise not only to me but to my surgeon as well. In "Russian Dolls," I explore the subtle nature of such surprises through the image of nested dolls. As a little girl, these carefully carved, brightly colored playthings evoked for me half-conscious associations to the womb, with its potential fecundity, awe and mystery. To my childish mind, these unformed images were always wondrous, exotic, exciting. Yet what happens when, in a moment of radical surprise, they are stood on their heads, and a bundle of cells intimates not life, but death? When growth becomes not bountiful, but malevolent and menacing? In my case, at the moment of surgical revelation, there was no surprise for me because I was conveniently anesthetized. My surprise was still to come, and perhaps when I wrote this poem, I was not yet able to confront it directly. Rather, in a gesture of resourceful empathy, I envision my surgeon's surprise as the dramatic moment of discovery occurs. True, it is a confrontation with evil, unpredictable, unexpected, horrible but above all authentic, a terrible yet all-too-recognizable perversion of an I-Thou encounter. Man recognizes monster, and monster leers back in response. Imagining my surgeon's suffering at this moment helped prepare me to face my own; his willingness to do battle laid important groundwork for my battle which was to follow.

The poem takes dramatic liberty with medical science. ESS can only be diagnosed accurately through careful pathological analysis, so my surgeon's surprise, though profound and devastating, actually did not occur until later. Nevertheless, something about imagining that moment of literal encounter between man and tumor pleased me in a perverse way. Because I could control the poem, if not the cancer, I willed into creation this diagnostic apprehension.

Diagnosis is only the beginning of surprise in the project of serious, life-threatening illness. If the medical condition is rare, as mine is, and eludes evidence-based prognostications, the patient herself may change in ways that are surprising. I am trained as a scientist and know the value of randomized double-blind clinical trials. But what if no gold standard protocols exist? What if the patient and the oncologist are, to some degree, flying blind? When science fails, we are forced to turn to mystery. Surprisingly (ah, yet another surprise), at some core level I discovered this development was neither foolish nor pathetic but rather intriguing and, ultimately, deeply consoling. Freed from the logical constraints of empiricism and reductionism, I encountered the world in a new way, opened



myself to new possibilities. In the face of the limitations of knowing, of prediction, of certainty, I began to pay attention to those inexplicable messages that regularly enter our lives through previously disregarded pathways. I allowed myself to become as innocent as a child, to listen with respectful curiosity to ancient wisdoms. Fortune cookies, miraculous stories, mystical predictions took on new significance. Did I suddenly believe in them? Perhaps not. But did they help remind me of the mysterious nature of life, death, and everything in between? Absolutely, and in a way that was always a surprise, even a wonder.

