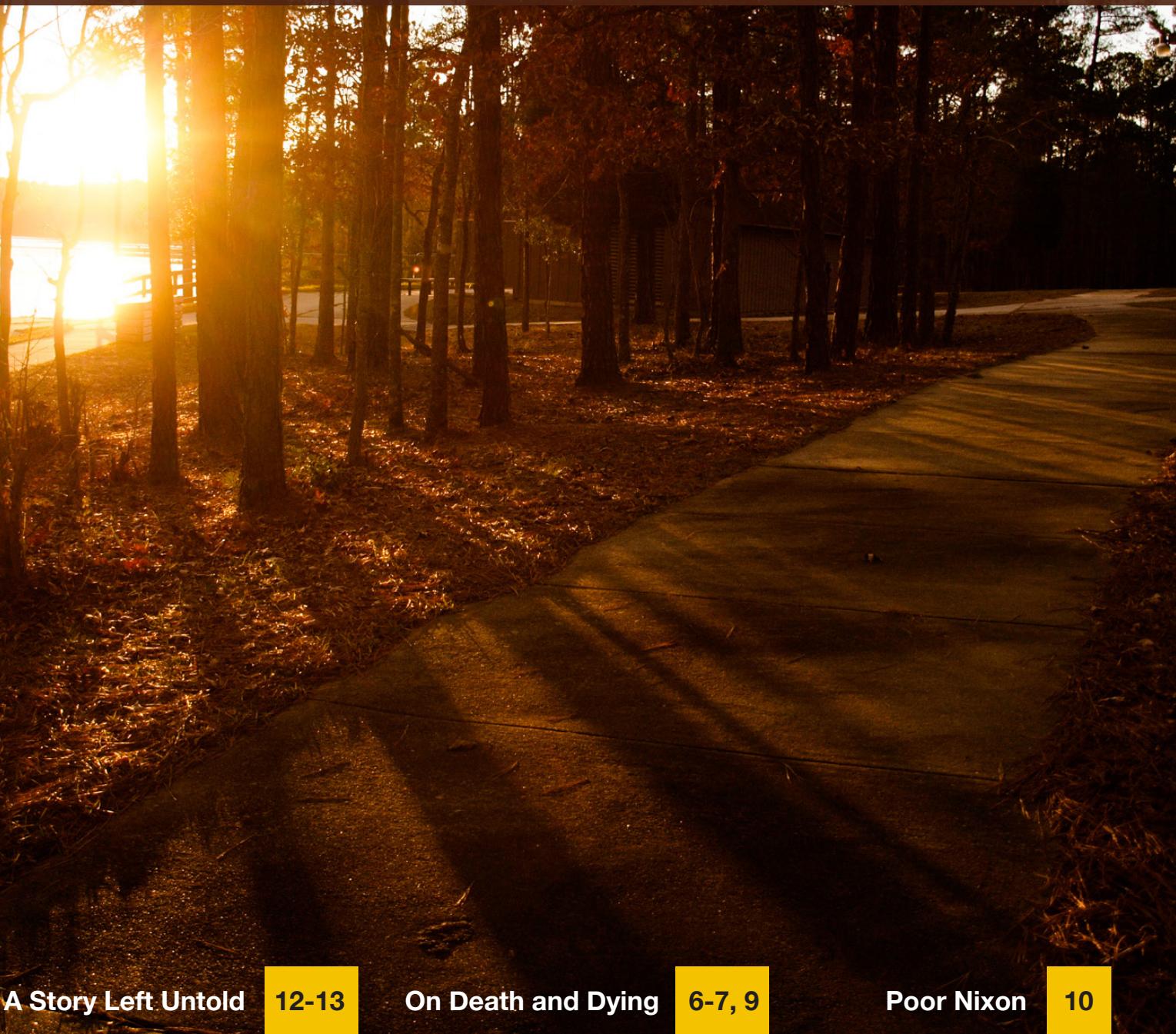


Duke School of Medicine

# VOICES

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A Story Left Untold

12-13

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# Voices

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# Anatomy Day 1

*A Life And Alive*

MATT ROSENSTEIN, MS1

The now legendary physicians Dr. Christine Montross (Body of Work, Brown), and Dr. Louise Aronson (History of the Present Illness, UCSF), and acclaimed social historian Professor Teofilo Ruiz (The Terror of History, UCLA) prepared me for medical education by teaching me that I have a duty to learn more about my patients, in life and in death, through experiential narrative. This is my minuscule attempt to learn by walking a toe in their footsteps.

Anatomy lab was the part of medical school that really scared me most.

Actually the thought of it quintessentially terrified me. The smell and fluid exposure was the tiniest part of that fear. Death scares me. And yes, as a clinician, I'm scared to see someone else die. Yes, people like me can go to medical school. I thought I would faint, throw up, be in the hallway in the first three minutes.

In part, it was the idea that I would be there while someone's mom, daughter, grandmother would be taken apart muscle by muscle.

Yet, it was more than this. It was the fact I would be there with what was left. Standing next to an incomplete set of organs, tissues, bones. Parts of a structure that once collectively felt the ultimate stressor.

That I would be left wondering at what point a person became the bone in my bone box.

I arrived expecting to come home and have nightmares. I'm home now, it's nighttime and I'm fine. I was reminded that I'm alive.

Our arrival felt like the first day of P.E. class in high school. Rushing to find a spot for our backpacks in the locker room, you could smell the industrial cleaning solution on the same sets of scrubs, t minus 10 seconds to game time with a long line to use the sink.

We knew what to expect, we wanted to know how we would feel.

We grabbed gloves, tied each others' aprons, and checked in. We stood with our dissection teams near the blue tarp-bag with our group number.

Our instructor reminded us how special this opportunity was. And then we unzipped, and as I opened my eyes again, I saw her.

Oh wow, she's... she's real, she has presence, she exists. She seemed at peace. Is she sleeping?

We uncovered a leg.

And I think I took a step back while shaking. Oh my God. Her legs were pale. Is she ok, I thought to myself. There was some instinct to try to help her. Subconsciously, I denied that she was dead.

Then came the face.

And she looked just like the people I love. And at that point I

knew I wasn't going to be able to cut. Hopefully I'd be able to stand and watch this.

We turned her over.

She had mass. She felt real, she felt like she could give someone a hug.

At first I watched from afar. Actually not really watching at all. Then slowly I peaked.

I saw the fat above the muscles grease my classmates gloves.

I saw the nerves separate naturally, the muscle uncovered.

It was real. This was the world beneath a life.

And it was personal, I knew everything I saw was in me too.

As she became more and more exposed, her finality became more and more conclusive.

She was not going to wake up. Not tomorrow, not next week, not ever.

She was a synonymous human structure, that couldn't live. A genetic carrier that could no longer differentiate. A person without a willingness, an eagerness, a commitment, a sense of self. She was gone.

And as I could taste a few of those saltier tears, I was reminded.

I'm alive.

Her feet looked just like mine. Her feet were still shaped the same as mine.

And yet I can move mine.

I can walk, I can jump, I can go play basketball, I can love.

I can go home and eat ice cream.

Wake up at 8:30 a.m., lecture by 9:10 a.m.

Test, notes, test, more notes.

Important.

So is being alive.

Going to honor her life by appreciating mine is alive.

Going to call my Grandma in the morning, and my Mom and my Dad.

And play basketball and really do the things that I love.

I'll make time for Grey's.

But first I need to enjoy my life.

And be grateful for that moment, the next one, not take anything for granted.

We're here and we're alive.

We are alive. And it is so amazingly awesome.

*Matt Rosenstein is an MS1 at Duke University School of Medicine*

# What is a Stump

*But the Abscence of Limb?*

What is a stump, but the absence of limb?  
Let sick life be done and new one begin!  
Faults of flesh repaired with technology,  
We're here to save you, we have the degree.

'Twas all I thought as I entered the room,  
A gay call to save this poor man from doom  
From ciggies and diet - things read in the book,  
Now sick appendage, I came and I took.

Rewind just a bit to understand me,  
With twinkling eyes, a surgeon to be.  
Oh the OR, as it called like a verse,  
And whispered, "come here, time to assist first."

Eight weeks did I wait and finally beep,  
Intern's off-duty, how high I did leap,  
And exclaimed to all, "time to chop a leg!"  
Ditched the banquet to scrub, no fear, no dread.

What is a stump, but the absence of limb?  
It happens to many, this time to him.  
Few med students have so lucky a chance,  
Now would be my turn to wield surgeon's lance.

But what if he knew my luck was his loss,  
How quickly aside kind words would he toss.  
Words that I meant could now meaningless be,  
If at that moment, he happened on me.

Excited was I, so much that I shook,  
Sprinting through halls, every short-cut I took.  
No thoughts of he, on whom I had rounded  
Proper technique, and Recall I pounded.

And when the time came, I focused, no smile  
Undertaking the act, strange all the while.  
"Good job" was earned, as I made myself look  
There, warm in my hand, lay unattached foot.

What is a stump, but the absence of limb?  
Bone and muscle covered with flap of skin.  
When limbs are septic, a cure it can be,  
Then back to the floor toward recovery.

He was drugged, alone, and absent one leg,  
I'd gone home, showered, then shuffled to bed.  
Before the daylight could bring morning gloom,  
I'd studied his chart, then into his room.

He lay as he did every morn before,  
Subtle smile shown as I opened the door.  
As my gaze moved down I became quite ill,  
This Being has changed, product of my thrill.

Had I not the foresight of this vision?  
Had I been seduced by the incision?  
Was I too young or ignorant to be  
trusted by him to hold the healing key?

What is a stump, but the absence of limb?  
At what point does stump end, and man begin?  
For man without limb is a stump you see,  
Loss affects all that a body can be.

But still this does not explain all I saw  
Crucibles differ, to any and all.  
What we can't do is push our perspective,  
No pity, no scorn, just be receptive.

Though his mass lessened, his weight on me grew,  
And revealed to me, another thing true.  
Than anything we think, a man is more,  
Than stature, than status, than his limbs four.

And when with this Man, we're trusted to act  
With blade, potion, or word, we have a pact:  
Acknowledge our aims while inclined to feel,  
Maintain above all, the honor to heal.

*Bradley Potts is an MS3 who is interested in Urology and enjoys fishing and watching Ohio State Football in his free time.*

# Death and Dying

ROBYN MICAL, ABSN STUDENT

October 10, 2013 · 20:30  
McCormick Hospital  
Chiang Mai, Thailand

A relatively slow evening in the emergency room, eight hours of my shift done and five more to go, I was hoping for some incomparable and exhilarating traumas. It was day six of my medical placement in the ED, but nothing up to that point could have prepared me for what was about to happen.

The ED at McCormick Hospital was a small, narrow room that barely had space for six beds. The double sliding doors to the ED were wide open to let a cool draft in, as it was a humid evening. At 20:30, all of those beds were empty as the staff and I entertained ourselves with old x-ray films. That moment of tranquility changed in an instant as a deep wailing cry bellowed out from the parking lot. Everyone in the room stopped what they were doing and locked eyes on the doors in anticipation for the trauma that was about to come in.

The next hour of my life was the scariest yet most satisfying experience I have ever had.

The moaning grew louder as a young woman, age 19, limped into the room. She was covered in blood and black char. Looking confused and horrified, she dropped to her knees, gasped for air, and threw her head back, attempting to scream but nothing came out. The ED nurses raced to her side and quickly escorted her to one of the beds. Just a moment later a young man, age 21, tranquilly shuffled in with nothing on but a pair of charred shorts. His entire body was seared black, as if he had just fallen through a chimney. A smell wafted through the air that was sickly sweet and deeply unpleasant. It hit the back of my throat, eliciting a visceral response in me to move faster, smarter and reach deep for a sense of compassion I had not yet discovered within myself.

This man emoted no sounds and no words but his eyes were filled with terror and anguish. I locked eyes with him and in that moment we shared a similar fear

that bonded us forever. I committed my whole self to him right then. No matter how daunting or grim things got, I would be by his side for any physical or emotional support he may need.

Two nurses and I placed him on a bed and drew the curtains around us to better assess his condition. At a closer glance, I noticed his eyelashes, eyebrows and hair were all singed off. The smell of burning flesh was now concentrated, thick and pungent, stinging my eyes and coating my mouth. I collected his vitals – BP: 182/114, PR:82, RR: 8, SPO<sub>2</sub>: 81. The head nurse handed me towels and bottles of sterile water and told me to put the towels on every inch of his body and pour the water without reservation. A chaotic dialogue took place between the nurse and the patient as the story of what had happened began to unfold:

*This young man and his wife were cooking dinner together in their shack 30 minutes out of town. Their gas can, which was hooked up to their burner, exploded with the young man standing directly next to it. Because their kitchen was a very small room, the explosion ricocheted off all the walls, charring his entire body. His wife, who had been on the outskirts of the room, was able to drive them to the hospital.*

The nurse did a rapid triage assessment and declared that this man had 85% TBSA burns with both 2nd degree deep full thickness burns as well as 3rd degree burns. I had limited knowledge on how burns affected the body at this point, but it was clear to me that he was in shock and edema was setting in very quickly. Only several minutes had passed and his skin became swollen, tight, and shiny. I stood next to him as his nurses were yelling orders across the room. He turned his head and looked at me with a tear rolling down his cheek. I returned his gaze with my undivided attention and a calming smile. He gazed back at the ceiling, closed his eyes and began coughing feebly. His nurses ran back over and shouted for an NG tube. I stepped back from him as he started to code and the entire team swarmed around him. As they intubated him, a stretcher was brought into the room and I was told that they were transferring him to Maharaj

Hospital, a nearby public hospital with a specialized burn unit. I was instructed to bring sterile water bottles and his chart into the ambulance and wait for them in there. I moved with haste and precision without contemplation. I was unsure of the plan but I was honored and relieved to be asked to stay with this patient.

The 10-minute ambulance ride to Maharaj Hospital was completely silent except for the pumping of oxygen. It was the calm before the storm. My eyes were unwavering from this patient as I watched teardrops stream down the side of his cheek and drip onto the side railing of the stretcher. Each teardrop was like a knife to my heart. Every fiber of my being was screaming to hold him and let him know he's not alone. It was clear his condition was rapidly deteriorating as the nurse told me his trachea was severely burned, his organs were beginning to fail and systemic edema was setting in.

As we pulled up to the ED of Maharaj, a team of at least 20, including doctors, nurses, burn specialists, plastic surgeon, cardiologists, and medical students, were all eagerly anticipating our arrival. We unloaded and went into a large area of the department dedicated to triage cases. It felt like I was walking into a slow motion circus from a nightmare. There was an audience that 'oohed and awed' at the severity of his condition, staff swarming around him poking and prodding him with every device available. His blankets were thrown off of him and he shivered uncontrollably for what seemed like an eternity. Someone drew blood while another took more vitals and set up for x-rays. Teaching doctors addressed their students, pointing out findings and quizzing them on their medical knowledge. And all the while, a living, breathing, thinking human had been lying there alone. No one said a word to him. No one asked him a question, updated or consoled him. Not a single person stopped to address any of his needs as a patient who was clearly dying. Surrounded by people but completely alone.

People started to clear out as they realized that they couldn't do much to save him. The adrenaline was gone and the

masses disappeared with it; it was as if he was no longer interesting or important. I was lost in translation and didn't have a clear understanding of what had transpired but I knew from looking at him that he was not going to survive the night. I asked my team what had happened and they confirmed that he was not going to live much longer. I asked permission to stand with him and address some of his basic needs. After getting their consent, I picked up the blanket at his feet and draped it back over his body. His once tiny, fragile, charred body had transformed into a rubicund swollen sac of fluid. I couldn't distinguish basic anatomical markers on any part of his body. His burns were raw, oozing and the smell was almost unbearable. I continued to move up his body slowly, gazing at every inch of him and finally got to his face. Although his eyes were swollen shut, tears were still slowly streaming down his cheek. In that moment, a commanding and life altering sensation took over. Regardless of what this young man was capable of feeling or comprehending, I was not going to let him die scared or alone. I bent down, placed one hand on his chest and whispered a quieting sentiment to him. I wiped the tear from his cheek and stood there holding him until he took his last breath.

My head fell and my heart sank as I silently said goodbye. I couldn't articulate or grasp any logical emotion for the next hour. During the drive home, I couldn't process what had happened but I knew I was proud of myself for the role I played in advocating for my patient while he was dying. It wasn't until I was in bed when a tidal wave of emotions washed over me and I cried until the sun came up. I stood strong in the midst of chaos and focused on my patient's needs in his final moments of life. I didn't speak the language nor did I fully understand what had happened, however I recognized his basic needs for companionship and security and gave him every ounce that I had to give.

I provided a freedom from suffering by simply being present.

*Robyn Mical is a Duke ABSN student who covets global experiences and cookie dough ice cream.*

# Bad News

## ALEXANDRA ROSENBERG, MS3

If you looked at this quiet street  
The cookie cutter houses and the tidy lawns  
And I said — guess which house  
Tragedy hit — you'd probably guess mine:  
Mine, with the overgrown lawn, cause Ed  
Won't come when I call; mine — the waste-high weeds,  
The loveless look of a part time home.

But you'd be wrong, you know,  
Because he came home last week  
In a dirty uniform and tired face  
And he said, "Remember our neighbor Sam?"

I know Sam.  
I saw him not long ago in front of his pretty home  
Maybe playing with his two big dogs, or working on his car,  
Or maybe I waved at his wife, or son,  
Or sighed over their lawn.  
Sam, of the kind face and super hero looks,  
Who fed our cat when we were at the beach.

Sam, who was with my husband  
On a nameless Afghan mountain  
One August day was shot-  
"Straight through the neck  
- nothing the medics could do -  
- just a fluke they hit him -"

News like that - a punch in the gut  
- *Injustice - a good man - for what?* -  
A crack in the façade  
of kind divinity.  
Maybe I could have prayed a little more.  
Maybe a grander gesture could be made.

What's left to say?  
One man came home and one did not.  
And I'm the lucky one again.

We rock our rocking chairs and drink a beer.  
We listen to the fading summer night.

*Alexandra Rosenberg is an MS3 at Duke. She grew up in NYC and has since lived- with more or less enthusiasm- in Texas, Georgia, Hawaii, the UK and most recently, North Carolina. She is currently surviving the frigid North Carolinian winters with the help of her husband, Trey, and her cat, Kitty*

## This New Normal

ANNA BROWN, MS3

In this crowded world  
We clamor for comfort  
Compete for cush jobs

Rummage our minds for  
A glimpse of that memory  
So sweet and forgotten

Pillage our hearts for  
Emotion, so raw and  
Unbroken, not dulled by

Long hours we spend  
Walking the hospital wards  
Or rather run to catch up

Quick step and quicker thoughts  
Fast pace keeps on moving  
Whether done or still living

That life you had always  
Envisioned, now may be  
A little out of reach.

This new normal is what  
It's all about these days  
Reframing reality

Your goals once so bold,  
Now steeped in obstacles  
Whether time or IV lines.

I wonder what it all means  
Most days

I wonder what we'll dream of  
Later on

When the black and white contrast  
Fades

And our distinctions all  
Change

Only time will tell  
How it will all play out.  
Until the last tick,  
We protect what we've built

And compete to complete  
Our life goals, still bold  
And unbroken by time.

*Anna Brown is an MS3 who enjoys creative writing, and pondering the meaning of life.*

## On Death and Dying

KELLY RYAN MURPHY, MS2

### The Inopportune Ride

I want two things  
Said the old man  
To die alone and  
To die in pain.  
“And why is that?  
Do people not  
Want the opposite?”  
Why yes, indeed, they do.

“But why alone?”  
Implored the bystander.  
So they remember me alive.  
“But certainly not in pain?”  
Alas yes, to feel alive.  
“I hope for your success”  
Good day to you, too.

And so the train emptied,  
Filling again; new faces  
To pass the time.  
And still the old man sat,  
Surrounded by strangers  
Free of pain, knowing,  
Today was not his day.

### Obligations

I'm going to beat this  
She said again.  
And with pursed lips,  
Upturned corners,  
We obliged her echo.

Though our ears,  
Our ears resisted.  
For had they not,  
For had they heard,  
We'd have been obliged.

And we were just not ready  
To correct her.

*Kelly Ryan Murphy is an MS2 and former Duke undergraduate.*





## Sweat Drop

CARLISDANIA MENDOZA, MS3

When she was a little girl  
scared and  
very very little  
she learned

Punishment will fix  
Fear is good, necessary  
Crying makes it worse

When she was a little girl  
scared and  
very very little  
she sided with eve  
Thinking everything would be simpler  
If it had been her fault

I am eve  
temptress, monster, war  
hidden in strong and clean and sweet

Born to be water  
that fills pots  
She yearns to be fire  
To be free to hate the things she loves

I am eve  
temptress, monster, war.

She was born of fire  
to be water  
and deserves no aloe  
for her wounds

*Carlisdania Mendoza is an MS3 who loves the beach, squirrels, and fairness in that order. She has a flare for the melodramatic caused at least partially by her early exposure to telenovelas.*

## Clay

STEPHANIE NGO

Soft, squishy, sometimes  
I run through your fingers and splatter  
    Onto the floor  
    Other edges  
Firmer and harder to move  
    I twist and reach, some  
    Tips hard  
    And rigid  
        Fall  
        And  
        Shatter

Give rise to softer roots that are malleable

Fingers reach from the inside

    Creating

    Mazes in

    My interior

    Hands

    Exteriorly

Touch me and I bend

But I am mounted on the same pedestal always

*Stephanie Ngo is an MS3.  
She enjoys coffee and frisbee  
catching dogs.*

## Poor Nixon

LESLIE JO MITCHELL

What strange unconnected things this man said,  
    “O ill done Dick” and “O well done Harry!”  
They dubbed him foolish, insane, crazed, and  
    mad.

    But oh, just then, Richard fell to Henry.  
What great prophecy he owned, and vision.  
    To test the prophet of his skill, the King  
Lost a diamond purposely. Quoth Nixon,  
    “Those who hide can find,” all astonishing.  
What fear had he of being clemmed. “Never,”  
Pledged Henry and rode off to hunt. Servants  
Snubbed the pampered loon. The King’s officer  
Locked him up to keep from torment. This good  
    Man sped up to meet a summons. After  
Three days returned, and found poor, starved  
    Nixon.

(Inspired by the legend of Robert Nixon c. 1467, the troubled prophet of Cheshire. The Shakespearean-style sonnet, composed in iambic pentameter, was written in an attempt to mix the mathematical peculiarities of the poetry style with a human story of Robert Nixon.)

*Leslie Jo Mitchell, RN BSN  
COS-C, is a MSN Nursing  
Education Student from  
Wilmington, NC*



# Dehumanizing the Human

AMOL SURA, LOUISIANA STATE UNIVERSITY SCHOOL OF MEDICINE

Death terrifies me.

So when our professors first herded us to the human dissection lab, through the foul-smelling corridors of the Medical Education Building, I grew apprehensive that I would be the fool who fainted at the sight of a cadaver. After a few introductory remarks from our professor, we opened our dissection tanks. As I drew the formaldehyde-soaked sheet from my cadaver, I stared down death for the first time in my life. Only a few seconds after the initial shock, a wholly unexpected feeling came over me—indifference.

Human dissection has evolved into a medical school rite of passage, the first test to evaluate whether someone is fit to enter the fraternity of physicians. To painstakingly clean and identify the thousands of structures within the body forces its participants into surgical patience, an appreciation for the human body's intricacy, and an unwavering commitment to education.

But an unintended, and maybe counterintuitive, consequence arises from spending hundreds of hours in front of a dead body: desensitization. This numbness comes not only from the passing of hours in lab, but also from the utilization of a person as a scientific frontier. Each passing day in the cadaver facility brings a new anatomical discovery. Findings such as a massive aortic dissection, pervasive hematomas, extensive muscular atrophy within the limbs and face, and a complete hysterectomy contributed to the metamor-

phosis of my first patient from a rosy grandmother into a three-dimensional textbook figure. Even the most humanizing characteristics of my cadaver—her hot pink nail polish and tattoos etched with a Biblical verse—faded into the background during our tedious scientific examinations. What remained was an educational tool, not a human.

Perhaps that's a good thing. Physicians shouldn't cringe at the sight of blood or an open wound. Early exposure to death and suffering is necessary in a profession where our entire lives will be spent dealing with it, in some form or another.

But it's also an extraordinarily unhealthy thing to forget the humanness of our cadavers. Ancient physicians realized this. Although the fathers of Western medicine, Hippocrates and Galen, dissected and vivisected thousands of mammals to uncover the anatomical basis of disease, they steered clear of human dissection. In Homer's *Iliad*, one of the only things that pauses the nonstop battle is the collection of and prayer over fallen soldiers. And by sacred Greek laws, homes that contained a newly-dead corpse were considered so desecrated that other villagers were prohibited from entering the home. In sum, remarkably powerful legal, religious, and social taboos surrounded the scientific investigation of corpses for over two thousand years, stretching into the Renaissance. This attitude persisted despite society's self-conscious realization that it hindered

medical breakthroughs for generations. Why were the ancients, even the most scientifically-minded ones, terrified of human dissection and dehumanizing their dead? And why has modernity since decided that it's OK to interact with cadavers?

The tension between the usefulness of dissection and its dehumanizing nature is omnipresent. As future physicians—bearers of the torch of humanism—we must come to terms with this tension in our own ways. This takes time, effort, and discomfort. But just as the Greek and Trojan soldiers in the *Iliad* once realized, sometimes we too must pause our battles, understand the gravity of our cadaver's sacrifice, and offer a prayer over a fallen soldier.

*Amol Sura is an MS3 at Louisiana State University School of Medicine, and a Duke undergraduate alumnus.*

# Looking Through a Breast Cancer-Stained Glass Window

*This piece is about one family's perspective on their mother getting and battling breast cancer. I wrote it after interviewing my parents for an Illness Narratives class to better understand our family's narrative of my mother's cancer. Of course, it is "stained" by my own perspective. Just like a stained glass window, each member offers a unique viewpoint that sheds light on a certain part of the illness experience. Each part of any story is a small fragment of a larger collage that helps onlookers understand a cohesive, beautiful whole. This piece aims to represent that fragmented work of beauty that was, and still is, my family's illness narrative.*

## Revelation

**Few Things Worse** I knew I had cancer from the moment I felt that parasitic little lump that took residence in my breast and sucked its lifeblood from my breast tissue. I touched it, gently, and then stopped touching it at all. What if I pushed the cancer out into my bloodstream? What if massaging it encouraged the little bugger to grow, made it think I was affirming its presence with my tender touch?

I just knew it couldn't be anything else. It was a primordial fear. Breast cancer was the one illness that I always dreaded and spoke of in tremulous, apprehensive, "what if" questions. I had been religious, too, even devout about my health. Damn near obsessed with having my husband check me for lumps. I never missed a yearly checkup. Never smoked, rarely drank. I suppose I could have exercised more, but I ate well.

I decided that stress was the cause... and God. Was I being punished? Dare I say that I blamed God for this? So common a thought, I know, but He was so perfect a scapegoat. Blaming a tame scapegoat offers such relief, but God was not behaving. It was as if this naughty scapegoat had turned around and bit me in the ass, maybe the breast, really, and then took pleasure in it with a wicked laugh.

I knew it was cancer. It had to be. It couldn't be anything else. As I sat in front of the doctor, only one thought was going through my mind. I rehearsed so I'd be ready. The phrase looped on a continuous circuit. It was like a song, a melody with its own distinct rhythm: "You have cancer, you have cancer, you have cancer."

"You have cancer."

"I have cancer."

The doctor's words and my thoughts

synchronized into the apex of my opus, the harmony that the entire piece hinges upon, the chord on which you hold your breath, waiting for resolution.

**His Prayer** Heavenly Father, Lord, please help me. Help my wife, help my children. I don't know if I can do this. Please give me strength. Please don't let my wife die.

**The Daughters** My parents were both home when my two sisters and I got home from school on a Friday. They were never both home when we got home from school. Something was wrong.

Alli: What's wrong?

Dad: Sit down.

We sat. Together.

Dad: Your mother had her doctor's appointment today to go over the biopsy results. She has breast cancer. (Pause). I know this is going to be really hard for you girls, but it's going to be OK. We have a lot of questions that can't be answered yet. She has to get her breast removed. That is going to be OK, too. We are leaving on Monday to fly to the States, and she has an appointment with some really great surgeons on Tuesday.

Jenni: (In a panicky voice) Is Mommy going to die?

Alli: No, Jenni, she's not going to die.

Mom: (Crying, just a little, with silent rolling tears). I could die.

Dad: Desi, you are not going to die. Girls, she is not going to die.

Mom: (Quietly, more to herself this time). I could die.

Dad: Here is the plan of attack. (Note: Dad is a man with a perpetual plan of attack. An Army officer, he divides challenges into goals and objectives, especially in relation to his family. At times like this, his training makes things easier. It is a reversion to what he knows, to what he's comfortable with). Jenni will be coming with us because she isn't old enough to stay in the boarding house and we don't want to separate her from Mom. Alli and Kaiti, you'll go into the boarding house while we are gone. I know it will be hard, but Mommy and I want you to stay in school and we have faith that you can do it. Can you do it?

Kaiti: (Crying) I don't want to do it.

Alli: Yes, Dad, we can do it. Kaiti, it will be OK. I'll look after you.

Kaiti: I'll want Mommy.

Mom: I'll want you.

## Tribulation

**Row of Lights** If I'm going to die from breast cancer, please, Lord, let it be now. Let me go to sleep in my operation and not wake up. If I'm going to die, don't let it be after I've given a long fight with lots of pain.

**The Operation** I had seen pictures from the operation. I supposed the surgeon would naturally want to document the process, the moment when he shot the first bullet in the war against my wife's cancer. The surgeon, like a master butcher, had flayed open my wife's breast. Proudly, he took a picture of the extracted flesh, sunny side up, so that the fat, muscle, and cancer tissue were displayed.

"We got all of it", he proudly proclaimed. Should I feel triumphant?

**Anguish** The sound of beating water against the fiberglass walls of the shower was not loud enough to stifle my wife's sobs. This was not a cry that wrinkles the sufferer's face at the eyes and forehead. It was a cry that twists and contorts the sufferer's entire body into the mangled posture of pain, loss, and despair. The anguish that was pouring from my wife's soul wrapped its unwanted arms around my own heart, and began a suffocating squeeze.

In this moment, she looked far different from the woman I married. In a soft voice I chanted, "Desi, Desi, Desi," both to calm my wife and remind me that she still was, at least at her core, the woman I married.

Naked together, I focused. With one arm I held my wife under her good arm to support her, my other hand cupping handfuls of water, pouring them over her head. Careful, careful, can't get the incision wet yet. It, the scar, stared at me, but I was stoic.

"Desi, Desi, Desi."

**Hair** I could not get away from my cancer. My cancer had become my identity.

During the day, the cancer was still with

me. Every interaction would remind me of my cancerous state. I hated it when people said, “Desi, you look good!” I knew that I didn’t look good, definitely not great. I looked like I was sick. I looked cancerous. For me, the attempt at kindness was instead an ugly and public recognition that, yes, this is a woman who is fighting cancer. We must affirm her. Support her. You don’t go around telling normal people that they look good.

Honestly, worst of all was losing my hair. I could hide my lack of breast with a fake implant that fit into my bra. The wig I used to cover my bald head sufficed only if the onlooker was about five feet away. Any closer, and my cancerous status was revealed. The wig was shaped well, but unmoving. The color was about right, but its texture was coarse and somewhat straw-like. It had a funny, plastic shine to it.

Not even the night offered respite from the cancer. Wasn’t it enough that I thought about it constantly during the day? No. Cancer stayed with me like the annoying song that gets stuck in your head and won’t leave, or the hiccups without a remedy.

Waking up in the middle of the night, I could feel my silk nightgown brush against my intact breast. What a glorious, feminine feeling. Yet the right side of my chest was empty. When your breast is taken because of breast cancer, the doctors relentlessly scrape every last cell of tissue off your chest wall. You become flatter than a pre-pubescent girl. The thin skin that was stretched tightly over my right rib cage was void of feeling, numb, and scaly from rounds of radiation. I stumbled to the bathroom.

As my sleepy eyes adjusted to the light in the bathroom, my reflected image came into focus. In the mirror, I saw a woman I did not want to be. The same silk nightgown that once looked beautiful lying against my pale skin hung awkwardly on my deformed frame. Filled with a breast on the left side, it hung limp across my bare right rib cage. My head was bald in patches, some hair still hung on with a death grip to my scalp. The same way I was holding on with a death grip to my life. I silently cheered on each remaining lock. Hold on, hold on.

**Self-Righteousness** In many ways I made my mother’s breast cancer about me. I was proud of the way I put on a stiff upper lip. I thought my mother, and certainly others, would admire such immense strength in a sixteen-year-old girl. I would exceed everyone’s, and my own, expectations.

I did not like boarding school. I felt like I could not relate to the other girls who

lived there. We had more in common than I wanted to admit: we were motherless. Our abandonment should have united us. But I felt like my family’s separation was distinctly different. It was not a choice: it was forced upon us. I considered myself a refugee, exiled to a place I had to call my home. I was lonely. I did not vocalize these discomforts often.

One night, the picture of my family that I taped to my wall fell down into the crevice between my bed and the wall. In the morning, I noticed the empty space and a panic surged within me. My family! What evil plot was this that destroyed any tenuous attempts I had made to keep my family close? The injustice! I fixed my makeup before heading out the door to class so no one would know I had been crying.

### Deliverance

**Expectations** Recovery is an interesting concept. I expected my wife to recover from her illness much faster than she did. She handled most of the physical challenges with valor and courage. The chemo did not entirely wreck her physically. She still worked quite a bit throughout the chemo. I was proud.

But my wife’s spirit had been crushed. She thought about death and cancer all the time. Her wounds healed, the rounds of chemo subsided, she began to gain her hair back, and I expected her to come out of the emotional despair that breast cancer had put her in. I needed her to come out of this. We all needed it. We were tired, in many ways, of repeating the lines, “No, you are not going to die”. This chant had become our anthem. It was the family’s new mantra.

I was getting angry, and Desi knew it. It was the aftermath that hurt our marriage. Collateral damage...

**Non-Speakables** In my family, there is one thing that you don’t say. You do not say, “I hate you.” I’ve said it probably eight times. Three times to my mother, and five times to my sisters. Every time I have said it, it hangs in the air for a split second before it delivers its nasty uppercut. In that split second, I always wish that I could take it back.

I’ve found another thing that you don’t say. You do not say that you are angry at your mother for how she dealt with her breast cancer.

You do not say she disappointed you. You do not say she is not your hero. You do not say you are bitter, or angry. You do not say she made you scared. You do not say that when you think about yourself getting breast cancer, you pray

you’ll handle it differently than your mom.

These are non-speakables.

### **Mom’s Words, Nov 4th, 2008**

“I don’t feel like I changed as a result of having breast cancer, and that worries me. Did I miss something? I still get stressed out, and feel like maybe I missed learning something. I hear about people who totally change their lives as a result of cancer (like they eat organic foods, or don’t eat sugar anymore, or exercise religiously) or they say that cancer was the best thing that ever happened to them! I know for certain, without a doubt, that cancer was NOT the best thing that ever happened to me.”

### **Thoughts on Writing this Narrative**

I was surprised at how difficult writing this narrative was for me. The process of asking my parents about their experiences and feelings towards my mother’s breast cancer was eye opening. Many of their answers were surprising, and it was difficult for me to integrate their views with assumptions that I had already made.

As I tried to convey my own emotions honestly, I continually thought about how much of this I’d want to reveal to my mother. On one phone call home, my sister asked me what my narrative project was about. My mother overheard, and interjected, “It’s about me being Alli’s hero.” My mom isn’t my hero, but that does not diminish what she went through or how much I love her. I won’t tell her she is not my hero. I’ll tell her that I’m proud of her for getting through cancer, because she has. She came through it in the end. I’ll tell her I’m thankful that her breast cancer is behind us. I’ll tell her I’m proud to be her daughter and that I respect her.

Most of all, I’ll tell her I love her.

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# The Story Left Untold

## Family Medicine

I arrived at Pickens Family Medicine clinic, alongside a crisp autumn breeze. I had arrived a few minutes early to prepare for another day. Days were always busy at Pickens, where patients had more comorbidities than minutes to discuss them. For every patient, in order to get ahead, I would commence on a journey through the corridors of EPIC with my mouse serving as my noble steed.

Visits for chronic disease management had fairly predictable stops. For diabetics, I would look up their HgbA1c and medication history to get a sense of their overall management. Then, I'd check their blood pressure and lipid panel to make sure they were being treated with the latest hypertension and cholesterol guidelines, which lead to everyone and their mother being put on atorvastatin. Lastly, I'd check if they had seen an eye doctor within the last year and if they had received their flu shot yet.

The journey became slightly more spontaneous as I tried to piece together what had happened since their last visit. Some patients had gone to the ED with acute flare-ups. Others were seeing cardiologists or nephrologists now that their chronic conditions had started taking its toll on their organs. By making mental connections, I could piece together a simple, concise history before even meeting the patient.

I tried my best to make this journey an objective means of previewing my conversation with the patient. However, I would sometimes find myself entering a room with an HPI already formulated in my head. The patient just needed to help me fill a few gaps in the story. EPIC made it all the easier with various templates one could follow - those templates could sometimes help guide the creation of the story and determine the probative questions needed to make it real.

It was less a habit of creativity, more a habit of convenience. While the best stories are those with nuance and complexity, the nature of the beast (i.e. 15 minute visits) made mundane, straightforward stories more appealing. Too bad these stories were rarely accurate.

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"Ms. M?" I said after knocking. "My name is Vinayak, and I'm a medical student working with the doctor today. Can I talk to you for a bit?"

"Sure, that'd be fine," She replied, softly.

She was a heavyset, African American woman in her 70s with horn-rimmed glasses of my parent's era and deep wrinkles beneath her eyes. She had a steady affect, as if age had touched her a few times too forcefully and left her tired and jaded. She had made eye contact for a couple seconds while answering, but was now staring at the floor.

"What brings you in today?"

"To talk about my diabetes."

EPIC had told me that she was in for a one-month checkup on her diabetes. So before coming in, I had scrambled through her EMR to get all her numbers. I also knew she had a full spectrum of active problems: diabetes, hypertension, high cholesterol, obesity, COPD, coronary artery disease, and end-stage renal disease. In a 15-minute visit, however, diabetes necessarily had to be the focus.

"How have things been going?"

"Well, I think it's been going fine," she said. "I haven't really paid much attention to be honest."

Her diabetes was not fine. Her numbers were headed in the wrong direction. Her HgbA1c had been holding steady for a few months but had risen quite a bit. Her blood and urine tests showed signs of worsening kidney disease. Thankfully, her eye doctor had noted stable diabetic retinopathy in his visit last month, but who knew how long that would last?

"Have you been able to measure your glucose at home?" I asked.

"Sometimes in the morning," she said.

"Do you remember what they read when you check them?"

"I really can't remember, but I think they looked OK."

I tried to get more information, following a standard script — has she had any episodes of high or low blood sugar? Has she had chest pains or shortness of breath? How about numbness/tingling or changes in her foot sensations? Changes to her vision? These questions led to a parade of "No... no...no...no..."

"Do you get three full meals a day?"

"Not really," she replied. "I've had a smaller appetite in the last month."

"How's your exercise regimen been going?" I asked.

"I haven't been working out much," she replied.

"I used to go to the Senior Center, but I've just felt too tired to go."

She shifted her gaze from the floor to my eyes before going back to the floor. A tear meandered down her left eye, getting trapped in a pool around her frames. Then another one. And another. She pulled out a tissue to wipe her eyes, moving her glasses up so I could see her bloodshot red eyes unhindered by refraction. She continued to look down at the floor, never looking up.

"What's wrong, Ms. M?" I asked, gently leaning

in.

"I lost my daughter two months ago," she said, softly. "It's been tough trying to get through that."

The story that I had constructed in my head before the visit had been reduced to ashes. All those lab values and previous clinic notes did not hold meaning today. All those scripted questions meant to guide the story's formation — are you having trouble monitoring your glucose regularly? Taking your insulin and metformin? Having side effects to them? Eating healthy and being active? — weren't going to be helpful.

Despite the chief complaint recorded in EPIC, this was no longer a visit about diabetes management. It was about so much more, and there was no EPIC template to guide that conversation. Nor should there be. The conversation that followed was unscripted, unhindered, unbiased by previous data. She told me about her daughter, how her passing had affected her, and how the grieving process had been since. Her daughter had issues in the past, but she had been working towards improving her life. But her life had ended in a freak car accident, leaving behind broken memories and a deluge of emotions for her mother.

Though Ms. M had become reclusive and detached over the month, she also had a strong spirit who was motivated to get better, both physically and emotionally. She was starting to feel better, reconnect with her friends, and spend more time with her living children. But in acknowledging the progress she had made, she was mindful of the things — such as her late daughter's birthday — that could set her back.

The emotional rollercoaster of grief was consuming so much energy that she had not been able to keep up with her medications and blood sugar management. Fortunately, she had volunteered this information during the visit — other patients might not have done so. Without it, any history on the patient would have been incomplete, and any recommendations made would not have been helpful.

Through several experiences like this one, I quickly learned how tempting it is to reduce people to numbers and former progress notes — to try to construct my own narrative for them before even meeting them. As much as I dislike myself for doing so, the inevitable time crunch of a busy clinic, and the well-intentioned effort to reduce wait times, has made it harder to avoid. It takes a lot of time to discover a patient is grieving and help them develop the next steps — it's so much faster to

pull up the PHQ-9 Depression Screen, calculate a number, and ask scripted questions. But by doing so, you often miss the real reason for the visit, the real reason they aren't doing as well as they could. You miss learning about their story, the real one — the story that often goes untold.

The clinical clerkship journey has been filled with several experiences that force me to reflect on many things. One of them has been the role of electronic medical records in the care of patients. While I have had several experiences where the information contained in them are vital, I have also seen instances, such as this, where it allows me to construct convenient stories that are devoid of color, nuance, or accuracy.

The sheer amount of data and information housed in EPIC is astonishing, but the connections between disparate streams are prone to bias and inaccuracy if not guided by the patient's own words. As a student just starting out on the medical career journey, I don't know the answer, but I hope to find that balance with experience — to discover the story for each patient that is often left untold.

## Radiology

I've found that sometimes medical experiences are less about the patient, and more about the procedure itself or information obtained through the procedure. This was especially true in radiology where most patient "encounters" were through a set of images and most in-person encounters featured sedated patients.

Overall, I found radiologists an impressive bunch, not just for their breadth of knowledge, but also for their incredible efficiency. In mere seconds, a radiologist could scan through a patient's entire body, looking for abnormalities as they quickly scroll through a morbid flipbook of one's innards.

They knew so much about someone's internal anatomy without laying a single finger on a patient. However, to fully understand what was going on with the patient, a clinical story often needed to be constructed. Much to the consternation of radiologists, the referring doctor typically did not provide this story. It fell on them to construct one through the series of progress notes housed in EPIC.

Radiology being my first rotation, I was forced to do this quite a lot for my own benefit because I barely knew what was going on. In some cases, it wasn't too hard. If I couldn't find a fracture on plain film, I'd go back to the primary care note and see where the patient had localized the pain. With more pinpoint focus, I could find the fracture

on my second pass — or at least convince myself I did.

One episode in particular impacted me. I was rotating through Vascular and Interventional Radiology and watching my first procedure — hepatic angiogram and arterial embolism. The patient had just gotten onto the operating table and been covered in surgical drapes. She was a middle age woman with a cheerful smile and lively personality.

"I've seen fire and I've seen rain," she was singing. "I've seen sunny days that I thought would never end."

"James Taylor?" asked the anesthesia nurse.

"Yes sir!" she replied, "I'm a music teacher and my students are learning that song."

"That's a nice one," he said. "Alright I think we're going to get started."

Her voice faded as the sedative agent started to kick in. The radiologist moved into position. They used fluoroscopy to image the liver's vasculature and then insert material into the hepatic artery to block its flow from the aorta to the liver. Since most of its blood comes from an alternate source (the portal vein), the liver is still able to survive.

The procedure I watched was a success and took less than an hour to complete. I figured the patient would be happy since I had an impression that most VIR procedures were curative. But I was still left puzzled — why would anyone want to block off the hepatic artery?

I stepped outside and quickly glanced through her progress notes. My answer came quickly as I noted most notes were coming from "Duke Oncology." The cheerful woman who I just saw, full of life and singing James Taylor, had terminal cancer of the bile ducts in her liver. This procedure was successful in that it cut off the cancer's main blood supply, but for the patient, it was a palliative, not curative, measure. She didn't have much time. On top of that, as a single mother, every note contained a social work addendum, discussing what would happen to her kids once she passed.

Beyond asking if I could watch her procedure, I had never met or gotten to know her. I had never met her kids or family. The only impression I got when I left the procedure was she was a vivacious person who had a successful procedure. But all I could think about for the rest of the day were the notes I read. But I didn't know the full story, nor would I ever. I would only know the fragmented clinical story that could be pieced together through progress notes in EPIC. And the fact that she would soon pass.

The clinical clerkship journey has been filled with several experiences that have forced me to reflect on many things. One of them is the role of learning about techniques and procedures. Knowing how a hepatic angiogram is done and how to interpret the information obtained is incredibly important, and often, it does not require knowing the patient at all. While knowing a patient's history can be important when reading their images, it isn't necessary to know more than what the reason for the procedure.

And I've learned that this is OK — for sake of efficiency and impact, it's OK to not know the full story. But when I don't, my natural curiosity often gets the better of me. The only way to learn more is through the fragmented notes contained in EPIC. And by piecing them together, one can discover the story left untold.

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PHOTO CREDIT: Billy Baumgartner (MS1)

