

NON-FICTION | SPRING 2019

ROOM 427

By Zainab Mabizari

I am sitting at the bedside of my father. He has only half his skull. His hair is partially shaved, gauze and tape wrapped along the incision lines reminding us all of what is no longer there, No Bone, shouting in all caps. He seems peaceful, his face has finally relaxed into a deep sleep. This is different from the last couple of nights when his labored, rapid breathing came out as disconcerting snoring. Every once in a while he starts violently coughing — a reflex from the tube that runs from the machine outside of his body down into his lungs. I have yet to know how to properly read ventilator settings, but the monitor reads Assist Control. The respiratory therapist tells me he's breathing five breaths per minute. The other thirteen is controlled by the machine. He is heavily sedated, to help with the post-surgery pain, to prevent him from reaching into his mouth and pulling his lungs out, to keep his body calm until it can restore. We don't know if he will ever be able to stand again.

I am torn, daughter and medical student, sitting at the bedside of my father. It is as quiet as can be when a human body is attached to every medical machine. My mother is sleeping on the chair. We have decided to take shifts for the night, and my hand refuses to let go of my father's clenched fist. It is late now. We were told the surgery that removed a portion of his skull was successful. The pressure in his brain is still increasing. We asked the doctors what's next. They said we wait. There is nothing left to do. We told them, please do everything. They say this is everything.

That morning, around 6-7am, twenty-four hours after my father was admitted for a stroke followed by every complication possible, the sun rose and lightly filtered through the blinds into the hospital room. I watched the light dance, first on the chair my mother was sleeping on, next onto the hard floor where I lay with a blanket, then onto the roses sitting at the bedside. Finally, dawn arrived on my father's face — eyes closed, nasogastric tube in, mouth elevated. The soft light stayed there for a while and I moved to the chair by his bedside. I grabbed his hand and wished him good morning. Eyes closed, he squeezed them in recognition. I sat there for a little bit, stroking his hand, placed a small green stress ball into his right palm. He moved it up and down. I repositioned myself at his feet, encouraged him, his eyes still closed, to toss the ball. Weakened, he was only able to lift his right forearm. The sun engulfed his right side — the only side moving. His mouth still agape, hair still on his head, eyes still closed, in between consciousness and unconsciousness. He is here, but not really here. I captured the moment, the light, his forearm raised and his hand bunched up in a fist in a photo. One day I'll show him this, I thought to myself.

It was after that moment everything went downhill. His lack of response, the elusive pressure in his head increasing to mortal level, the flood of hospital staff that pushed us to the

corners of the walls and forced papers into our hands with life-saving decisions that needed to be immediately made. We didn't know how dangerous the decline until after the surgery, when the neurosurgeon told us we made the right decision. He saw the status of my father's brain as soon as he took the drill to his skull. Any moment in hesitation longer and my father would've been lost forever.

Forever is an odd word, isn't it, because nothing is forever. But we hope, don't we, that forever never leaves, that we stay as we are. We never think of what will no longer ever be until it is not there, and then we fill the emptiness, somehow. Don't we?

My father, in the photo, is himself in a hospital bed — a strong fighter, one who matches adversity with grit, one who has survived war and famine, who has moved countries and built homes, one who is not yet willing to let go. Him, slipping in and out of consciousness, him my father, him who had no reason to have this stroke, to have taken us all by surprise. Him comforting us the best way he can, a raised fist salute. Him, half his brain destroyed by an invisible little clot, by medical intervention, by all odds stacked against him. My father, right now... I am not sure where to find him.

I'm sitting at the bedside of my father, night come, the hospital silent to the sounds of the intensive care unit, gazing upon missing bone, thinking of how different this morning filtered into the room. How brief the tender moment we shared before the sudden decline, the stat wheeling into the operating room while his consciousness was dimming, the pulling from the grasps of a tempting grave beckoning him in. Time has converged and my mind is racing, racing, racing as the hour hand on the clock speeds up. I am trying to think of our last full conversation. I cannot remember. I know I ended with I love you, this we always do. I am trying to think what could have caused this. My mind is flipping through the pages of medical textbooks I have read for any piece of knowledge, any high yield information, anything that could give me an answer. Why didn't I stop this, why did this happen, where did we go wrong, all the labs were fine, all the blood tests were good, what happened?

Stop the medical jargon.

He was exercising, he was eating well, what happened.

You don't need to solve the mystery.

He was talking, he was walking, he was still carrying the sky on his shoulder, when did it decide to collapse onto the ground, why did this star flicker out, we are never granted burdens we cannot carry yet maybe it was too much, too much for the delicate vessels that weaved in the universe of his being. What is he thinking right now, these neurons that still fire, what land must we pull him out of? Where is he, where is he, where is he?

Not here.

My mind is roaring -- my father, phone call, medical school acceptance, his tears of joy. My father and me, drinking coffee, every week, catching up. My father, white coat ceremony, sitting front row, big smile, taking pictures of the first doctor to carry his name. My father, an orphan. My father, an immigrant. My father, never asking for anything. My father, three years old me, sitting on his knee, both of us crazy curly hair, both of us million dollar smiles. My

birthday, his favorite photo. My father, last text, please answer the phone. Me, in the clinic, me, in class, me, busy, me, studying hard, no time, studying hard, a one-year countdown to that medical degree. My father's phone, stolen in Paris, thousands of pictures and videos of us, gone. My father, waiting to watch me walk across the stage, floating green robe, hooded, doctor. My father, waiting to walk me down the aisle. My father, wait for your grandchildren, please.

I caught a glance of his chart the last time a nurse walked in, read words that pierced me: significant morbidity. Never will walk again.

The doctors asked us earlier, "Are you sure this is what he wants? His life will be different. Does he still consider this quality?"

We discussed. Consent, still full code. Consent, do everything.

"Is this his wishes? Are you sure?

You, the family, must take care of yourself.

This is a long journey if he makes it.

Do not ask about what will recover now, we are fighting to keep him alive.

Significant mortality. 90%." The neurologist awkwardly patted my shoulder, then removed his hand in pity as if grief was contagious.

How does grief endlessly pour? Is there no end to this pain? How can the mind think when it's clouded in fear, what are these memories that rush? How can the future and the past collide, must I erase what I always thought was in store? Trying to seek clarity. I don't know how time can continue to pass.

Thinking of the charts, flipping through memories at my father's bedside. I cannot decipher what is daughter and what is medical student. My mind is racing, racing, racing. I watch the hour and minute hand perfectly align. Midnight.

Remember to never talk to your patients like this. Remember to sit down with them. Remember how it feels to have the arctic winds force itself in, clothed in white coats. Cold fronts arrive with stethoscopes here. I wonder if I place my own upon their chest if I can hear lub dubs. When did they give it away, that warmth that emanates.

You have only known what happens while wearing a white coat. You have only walked as part of their teams, presented outside these doors, wrote their jargon into medical charts. Remember how it feels to be on this side.

Never forget how it feels to be on this side.

"What does this mean?", my mother asked the neurologist. "All he needs is to be with his children. To talk, tell his stories, have conversations with his friends. So what if he cannot walk. He is not ready to go, no, not now. So what if he neglects half the world. He still recognizes our faces. So what. All he wants is to be alive. This has happened to others. I have a half-brother, he fell down one day, and it took him a year to walk again."

"Not like this, mom." I wrapped my hand around her arm.

"Others have survived this before."

I flipped through the CT scans, but she cannot see what I have been trained to see.

"Not like this, mom."

My father, what is receding in that head of yours, what parts of yourself have already gone back from where they came. My father, still alive. My father, fighting.

My mind quiets. Go to sleep.

My mother taps me on my shoulder. A line goes off, I silence it. Watch as the electrical currents record on the telemetry screen, find comfort on the rise and fall of the p, q, r, s, t. I am watching the steady pulsing of monitors. Watching the steady rise and fall of my father's chest.

Student. Medicine belongs to time now.

Daughter. Go to sleep.

Zainab Mabizari is an MD candidate at Baylor College of Medicine and is currently pursuing an MSc in Narrative Medicine at Columbia University. She is a writer, poet, and storyteller passionate about health policies, women empowerment, the care of the underserved and underrepresented, social justice and activism as it pertains to medicine, and medical humanities.