

# The Significance of Marigolds

*by Devan Kansagara*

The monsoons had yet to come and dust filled the June sky. As the sun eased into the thick horizon, the indigo and red of the summer evening oozed over our heads. Each color bled into the white stone courtyard, busy with aunts, uncles, mothers, second cousins, fathers, in-laws, and neighbors. Pink roses and yellow lilies sprouted from beneath a wall. A group of women carrying mounds of orange marigolds entered the courtyard. Behind them trailed a smaller group of women with tear-strewn faces, amongst which I recognized the face of my aunt.

I was ten years old and was visiting India for the summer. I was with my uncle and grandparents in Upleta, a village in the southwest of Gujarat state, for the funeral of my aunt's father. I had always known her as a smiling, imperturbable and good-natured woman, so I was confused at the sight of my aunt wearing this mask of grief. I remember playing with some of the other boys – a made-up game with a tennis ball. As I saw the group of grieving women, I recognized something profound had happened. I knew why we were there, but had little understanding of what it meant. I put down the ball and stepped to the side and, with my head lowered, I tried to feel something profound.

To recognize significance and to feel significance are two vastly different things. After I searched my thoughts for several minutes to try to understand what was happening, I was distracted by a line of ants that marched towards the wall. I gave up and picked up again with our game. A scrawny ten-year old boy cannot carry too much weight.

As a second year resident in the intensive care unit I was called by the emergency room to see Mr. H. He was 81 years old and had been brought from home by his family. He had become listless, fatigued, and short of breath over the prior two days and could barely muster much more than a breathless whisper. "I'm tired," I heard as I bent my ear towards his mouth. I held his hand and he gently squeezed

mine. Several intravenous lines coursed towards him and disappeared under the sheet. The sterility and order of the crisp white sheet imposed a calming effect on the internal chaos of his failing body.

Several years ago a heart attack had weakened the pump and circuitry of his heart. The number of medications prescribed to him doubled and the cardiologist inserted a pacemaker. His body, like an old abandoned mill town, rusted gradually over the next few years. A widower, he moved in with his daughter who filled his pill box weekly, helped negotiate the doctors' appointments and kept him company. "That mind is still sharp as a tack." The daughter's voice wavered and she tapped her fingers on the bed railing. As I examined her father, she went on to describe him as a proud patriarch of the family who had been very much in control until recently. His jaw was still strong and straight, and I could imagine how he may have looked forty years earlier enforcing curfew or sizing up his daughters' boyfriends.

Mr. H was suffering from an overwhelming urinary tract infection and an exhausted heart. I explained what was being done to treat him – he was on antibiotics and a medicine to elevate his blood pressure - and what more could be done. I also explained how sick he was and the options if his condition were to become even more serious. Mr. H

drifted in and out of sleep. He did not want “the tube” or CPR according to his daughters. He managed to nod in agreement to this. But the patient and his family were comfortable with other aspects of ongoing aggressive treatment.

We brought him to the ICU where he soon required two intravenous medications to elevate his blood pressure just enough so he could still whisper to us. I spent the next few hours, along with his daughters, largely by the bedside, making tiny adjustments in medications. The daughters quietly recounted old family legends so familiar they could each finish the others’ thoughts and punchlines, but the anxiety they must have felt still showed in the corners of their eyes. His lungs soon began to drown in fluid. We were failing to cure him and simultaneously failing to provide comfort. I leaned over to talk with Mr. H. and explained our precarious position. As if he anticipated my next question, in between his increasingly desperate breaths, he asked to be comfortable. His daughters each lay their hands upon his shoulders in tacit agreement. I looked again at Mr. H. and noticed (or, perhaps, imagined) his eyes soften and his jaw relax. I gave some morphine for his breathlessness. When they were ready, I explained, I would stop all medications except the morphine and I left them alone to tell stories and remember.

I was called at two AM - Mr. H’s breathing had essentially stopped. Earlier in the evening, the cardiologist had quietly explained how to inactivate the pacemaker should we decide to pull back and let him die. I entered the room, closed the curtain, and brought over the machine that would deprogram his pacemaker. He looked comfortable and a clean white sheet was pulled up to his chest. His tell-tale electronic heart glared at me from the monitor. I placed the magnet over his pacemaker, punched a few keys on the computer and waited. The beat slowed but persisted. I punched more keys – nothing. I rebooted the computer and tried again and still the green tracing stared back at me. I felt like a floundering young Frankenstein toiling away at this bionic being. Of course, Mr. H. had already passed peacefully – he was brain dead, had stopped breathing, and had no pulse. But I still felt a nagging uncertainty. I had had the privilege of witnessing this man express with his eyes a serenity and understanding I could not have myself conceived of as he lay waiting for death in the ICU. And now I felt I had somehow failed him with this machine and that his ghost or spirit was trying to tell me something with the insistent blip-blip on the monitor.

I stepped back and thought about my aunt’s father and the funeral in India. I had been frustrated then by my inexperience, my lack of understanding. Rather than being on the sidelines, I was by this man’s side, I was “doing something”. The absurdity of this last thought struck me as I saw exactly what I was doing. I closed up the computer and turned off the monitor. I thought of myself as a witness

to this man’s last delicate moments. I thought of my own father, held my patient’s cold hand and lowered my head.

My father was hospitalized during my second year of medical school. He had seemed tired and distracted Christmas day. Over the course of the evening he grew more and more confused. The change was insidious, it crept into him. I couldn’t recognize his illness, but I could recognize something wasn’t quite right. We called a physician-uncle who suggested bringing him to the hospital. It wasn’t until we got there that I noticed he was breathing harder than I was. He somehow looked much sicker to me in this place that hunted for illness. In the emergency room I watched critically as the triage nurse declared him fit enough to wait in the waiting room after a two minute evaluation. But that was too fast, I thought. She didn’t even listen to my father’s lungs *under* his sweater. You have to listen under clothing, I silently protested – even a *second-year* medical student knew that. Every detail screamed with immediacy.

After what seemed like hours the doctors diagnosed my father with a pneumonia. He was admitted to the hospital. The first few days were marked by anxiety and then relief. He was making slow but definite progress. The fever was down. He had woken up. By the fifth day, though weak, he was well enough to leave the hospital. I went home to catch up on life and sleep.

That evening an uncle called to say he had been readmitted, this time to the intensive care unit. His lungs were failing and he was on a breathing machine, my uncle explained. I rushed to the hospital to be “greeted” by a cacophony of alarms and bells for my first walk down an ICU corridor. The hot white halls were nearly blinding. I was unsettled in this other-worldly technologic future.

I remember only snap-shots, each with precise detail. Each room with its glass doors invited a glimpse of the very personal still-life contained within. *Elderly woman in pink sweater, bent over unconscious husband and whispering. Two small children, arms intertwined, asleep on chair, waiting.* I would make my way daily to the room in the far right corner to paint myself into our own still-life.

My father lay unconscious, tangled amidst a thicket of wires and tubes. His chest rose and fell in compliance with each sigh of the breathing machine. I quickly grew used to its uncomplicated rhythm; I was startled each time my father coughed and interrupted it. With the abstraction of lines created by the various IV’s and the dizzying display of numbers on the monitors, there was no good place to rest my eyes. I often just stared at the wall, or at my book.

The first day was terrifying – I knew and understood nothing. The jungle of technology surrounding my father was little more than mysticism to me. Nurses would come in periodically with some concoction or potion and a

comforting smile. I had little sense of control over the situation initially, having no choice but to trust what they were doing was the right thing.

We were studying lung pathophysiology at the time in medical school. While I was sitting at the bedside waiting for change - waiting for my father to wake from his deep sleep - I read about the lung and why it failed and I imagined they had written this about my father's lungs. It was comforting, in a way, to begin to learn (a very small amount) of what was happening. I slowly felt like less of a foreigner: I was taking short steps to citizenship in this new land. I felt fortunate that I could understand how this machine the book described could help my father. My initial discomfort with what was initially apparent shamanism was replaced by a naïve reliance in the faith of science.

I had somewhere to rest my eyes. All of those numbers were taking on meaning. By the end of the first week we had fully invested ourselves in the ticker-tape of numbers. *The PEEP is down to 10! The FiO2 is down to fifty percent!* Clearly the changing numbers on the ventilator meant something. There was a whirlwind of change daily. Plenty to keep our minds occupied. There are a few doctors in my family and this generated a daily barrage of phone calls to the ICU. *How was the PEEP today? What was the FiO2?* I had little chance to wring out the excess of my number-soaked brain. For the first two weeks we hurtled along in this medical freight train, with little chance (or desire?) to slow down and appreciate the big picture.

Dr. L was a middle-aged Indian in charge of the ICU. Later in medical school I would learn Dr. L was regularly deified by the students and residents as a brilliant physician. I knew nothing of this at the time, having little occasion to marvel at his medical acumen. At first, Dr. L was simply a collection of idiosyncrasies and appearances: his hushed voice which often trailed off in a mumble, the pictures of his children (my age) in his office, his droopy eyelids. When he brought us into his office, he sat behind his desk and leaned back and paused. I was afraid he had fallen asleep. Instead, in soft, but direct, strokes he painted for us the big picture. My father's lungs were drowning in fluid likely because of a reaction to his pneumonia and severe infection. He was very ill and one out of every two people like him would not make it. He delicately helped us slow down. As I asked for more numbers he gently comforted me with a hand on my shoulders. I let some of my weight transfer to him through that hand. I had time and space then to grieve slowly.

I realize now the idea of comfort is one that often comes late amidst the chaos of the hospital. Though he was never directive in his approach to our family, Dr. L made it possible for us to spend time thinking about abstractions and spiritual needs. It was the end of the third week in the ICU and my father's lungs were failing to struggle back. Ominously, his kidneys began to fail as well. The dialysis

machine just added more beeps and tubes to the growing web. Caught in the center of this, my father actually looked calm. Plenty was being done to him, but little was being done for him and we were, in the meantime, getting pushed out to the periphery of the room. Stepping back it was clear we could provide comfort, but little else.

And so we slowly let go. I was exhausted, confused, and even felt like I had somehow betrayed my father. But I also, strangely, felt relieved. I think Dr. L made it possible to feel this relief, to step back and ask questions about souls and spirits rather than machines and medicines. Perhaps it was the look of peace we saw settled into my father's face fully expressed – the same look I would relate to on Mr. H's face. Or perhaps it was the dissolution of daily suspense that was a relief. By withdrawing care I felt as though we could help by cutting the perfunctory ties that kept him tethered, unnaturally now, to that bed with its crisp, clean white sheet.

We came in to change my father's code status. Dr. L was waiting in the hall. It was the end of the third week in the ICU and I must have looked ragged. Dr. L took a step towards me and embraced me with both arms as if I were his son. I looked up and thought I saw his eyes moisten. In a sense he had absorbed some of my emotion and my head felt just a little less heavy.

In the transformed room at the far right corner, now bare of machines and monitors, our family gathered around my father for the last time. I felt some comfort in knowing we were all there. Despite his apparent undisturbed slumber, we had faith that he was very much aware of his surroundings and that he had some degree of control during these last few days. *See, we said, he waited for us all to be here.* We are each ultimately in control of our own journeys.

The doctors could not tell us when he would pass, so we all went home to rest.

At one o'clock the next morning the phone woke me. We shuffled down the eerily dark early morning hospital halls and gathered outside the ICU. Here were the aunts, sisters and cousins with their marigolds and somber saris. They sang songs in an impromptu religious ceremony while we went inside in small groups to pay our last respects. The lights had dimmed over the other still lifes and the ICU slept. The other families would wake to see a new still life in the room at the far right corner.

I thought again of the funeral for my aunt's father in India and was overwhelmed by the memory of the tumult of emotion and depth of feeling that had flashed across my aunt's face. Without the substance of empathy, the hollow sense of significance I felt as a child had collapsed under its own weight. And now, standing in the ICU with my father, I was dripping with substance.

A sleepy-eyed intern with rumpled hair called me over as I left the room. He had likely also been woken in

the middle of the night by a phone call to come attend to my father who had just died. He was filling out some paper work. He asked from behind his desk if we wanted an autopsy. We had heard theories about what may have happened, but the doctors still did not have a full explanation. At that point, at the end of the interminable three weeks in the ICU, it mattered little to me. My family had discussed this earlier and I gave the intern my answer. *If you think it will help you and others learn then please do the autopsy.* With a blank look on his face he muttered, *yeah, well that's kind of the idea.* I think I had to sign something and I walked out. Like air being let out of a balloon I diffused through the last few religious ceremonies and the drive home and I collapsed in bed.

I never did get the results of the autopsy. I have never actively pursued it. In part, I think, it is because I am hesitant to let my father's last weeks be explained by a stranger with a pathologist's license. I am abhorrent to let my own understanding of events, wrapped in a soft spiritual gauze, resemble my work.

In medicine our patient's experiences often exist within the confines of differential diagnosis and probability and explanation. It is more comfortable this way. It is easier to build a structure around a patient that we can identify and understand than to work with emotional uncertainty. When I try to put a patient's experience in the context of my personal experience, a deep chasm gapes at me. I have, on occasion, struggled to use those three weeks in the ICU with my father as a kind of emotional gauge. It is an active process, one that involves a concerted effort to conjure those memories and feelings. I don't like to do this often because it is exposing and it forces me to aspire to an impossible goal in my work. But during those moments I have thought about what I was feeling and how I remembered those weeks, I feel I have been a better doctor. The science of the ICU did not matter to me as a family member. Rounds and call and report and sign-out were non-existent. But there are details I can remember vividly and exactly and that matter very much in my memory of events. That Dr. L would open his arms and reveal a more vulnerable part of himself meant a great deal.

The intern asking for an autopsy also was etched into my memory for different reasons. I am sure I have been that intern - exhausted, trying to get through the night, checking off the box next to the note – *ask for permission for autopsy.* And at those moments in my training I found it difficult to access my own experience, my own personal sense of empathy. During those moments, I likely had only a vague sense that, for a family member of a dying patient, details are devoured and each gesture seen through tear-blurred eyes gains critical importance. I remember clearly that the intern did not come out from behind the desk and did not offer a hand in condolence. I remember the color of his scrubs (green) and that he wore glasses and that he was

Indian. I only hope that as I gain experience, more families will remember me as Dr. L and not as the tired intern.

We are witness on an almost-daily basis to the blindingly significant life events of our patients and their families who are often strangers. I believe patients and their families want these witnesses to be more than passive bystanders giving orders, watching an electronic heart beat diminish. And often we are the sole witness, the only person who can lend some immediate significance to this moment of passing. I wonder at times who was present when my father was pronounced dead. I wonder if a nurse may have held his hand and paused for a moment and thought about an uncle. Or maybe the intern, sleep momentarily washed from his eyes, recognized in my father his own father and thought for a minute about the significance.