They called my father “hypertensive,” elevated blood pressure beating against kidneys, eyes, mind. A cuff tightened in a silent room, recording numbers that “may cause complications.” They gave him lisinopril. He took pills until an orange Rx container emptied. With no symptoms and no renewal, he continued his regular life—adding salt to every frying pan, responding to ten more emails, weaving the streets of Boston.

Now, he was diagnosed with “diabetes.” Everything changed: he stopped having pasta, grabbing chicken instead. He added butter, removing sugar. He picked peanuts, ignoring the chips. He chose to take each pill. Diabetes seemed more serious.

I asked my father why he invested in his diabetes when other health problems had been there before. “When I heard ‘diabetes,’ dying seemed real.” He paused and breathed slowly. “I am afraid.”

As his daughter, not the medical student, I nodded, hoping I had waved warning flags early enough while respecting choice, trusting my father’s physician to do the doctoring. For her, the negotiation of health opened: Can you remove soda from your diet? Sweets? Monitor glucose? Your medications? These new demands delivered like wooden slabs, wrapped and packaged on a wet foundation as my father would return from his appointments bewildered, “but my numbers were fine last year.”

Through my medical and public health education, I have engaged in the interdependence of the social context and medical aspects of health where a patient’s understanding of their health either idealizes or rejects the ability of medicine. The 92-year-old wanting surgery though our attempts gave only one more day. The young woman struggling with painful sex for a year until our examination revealed a closed hyman. Like my father’s understanding of his disease, our role as medical providers develops when a patient is willing to alter their norm and their body. The physician empowers the individual while adapting their skills to meet the patient’s goals. However, this takes time and with hours of billing time, layers of protocols, and insurance, how does the patient not become a number? When can the patient be lucky enough for our time? The patient demands the forefront of every aspect of medicine with our conversations and interventions living in a context. How do we connect with them in protocol, regulation, and checklists?
On my surgery rotation, the resident said while we closed the incision, “Building trust is essential to a good surgeon. You cannot forget you are caring for a person, but at the same time, you cannot let that consume you.” Before proceeding with an exploratory surgery, we sat bedside to Carol, a 50ish-year-old woman with radiation induced abdominal pain and crippling diarrhea after bladder cancer treatment. The surgeons explained the surgery could weaken her already limited mobility and likely do nothing for her pain, diarrhea; potentially even causing harm in her thinned muscles and scarred skin. However, for her, surgery meant hope.

After removing thick fibrotic fat and numerous tissue adhesions the day before, we entered her hospital room like a wave of white coats, fumbling with sea foamed hands.

“The surgery went well. You did very well,” the resident explained. I resisted the urge to drop my jaw. My eyes widened, for I would have explained how, with such disorganization and changes in anatomy, we’re doubtful the surgery did anything of good. Instead, we surrounded her bed and cocooned her recovery with a smile and repeated, “you did well.”

The sunrise blanketed Carol’s hospital bed and she grinned, thanking us. Again, and again, the surgeons made their rounds, waves coming and going on the beach, describing how well surgery went. We removed your gallbladder. I would see the gangrenous organ bubbling with cautery and inflammation eating into the liver. We removed a section of your bowel. I would see the scalpel widening laparoscopic holes, causing more trauma. Despite the inflicted trauma, every patient comforted with the perception that the surgery went well. Medicine, and certainly surgery, is a human art form, which comes with human creativity, skill, and imperfection. Surgeons would say “pull harder, the skin is stronger than you think” and the seasoned, “perfection is a surgeon’s worst enemy.” Surgeons succeed when they foster the human body’s strength and spirit.

Though many of the surgeries deferred from the ideal anatomy and technique, surgeons adapted their skill to heal in each case. Protocol offers the best for a population; however, the body and a person’s beliefs of their body limit the capacity for health and medicine to heal. During a rainy weekend shift after leaving the trauma bay at 12:30 am, the surgical resident said, “one out of one hundred survive penetrating trauma to the chest.” The 16-year-old black male arrived with chest compressions and his body was tossed to the bed. Within seconds a scalpel opened his chest revealing rib nubs and a violet heart. Within a minute, surgeons extended the access to the chest and blood plummeted out like an ocean wave crashing over sand, onto white sheets where black jelly formed in seconds. Our hands wrapped around the heart to push blood to his brain. The descending aorta was clamped, but his extremities were already ashened.

Eight minutes in, the attending announced, “The bullet went through the greater vessels; there’s air bubbles in the coronaries; I’m going to call it. Time of death 11:58pm.” The heart will never beat again, even with our attempt to deliver liters of blood through plastic tubes. The room processed that 99 out of 100 end with this outcome. With a pause, the attending said, “let’s hang out a bit after this; does anyone feel they want to talk.” The teenage body lay there. The intern came over to me and asked, “you okay?”

“Yes,” I responded slowly, locking eyes with her and seeing a boy walking the street, glancing over his shoulder, getting hit and lying in this white room with medical strangers. We pulled off our blue plastic gowns. Mine stretched, instead of ripping, and I felt like the novice skier taking
wide turns down an icy mountain. The resident had already left the room and I yanked the gown away, twisting dark gloves into trash. Catching her in the Worcester night rain, she began the lecture of protocol, mumbling the end of every sentence: “I couldn’t do this everyday…won’t lose sleep over it…”

A week prior, I had seen my first code; my intern nudged me to leave before the family arrived. Ten feet down the hallway, my intern began to explain the protocol of epinephrine doses and shockable rhythms. Now 20 feet, and 50 feet away from the room, his words changing from whisper to normal speech. Regardless of distance, the protocol seemed muffled against my heart still in the patient’s room, the cracked ribs and the memory of her adult children holding her hand before surgery, and me, pulling her bed away. Where was love in the directions to help?

Protocols and approaches come from years of practice and research to guide the team and impact the individual—the one out of 100. Even within the protocol there’s human interpretation and as the student, I received a holey quilt of lectures with uneven and overlapping squares. Surgeons differed on their views: open the chest within 10 minutes, 15 minutes, vitals within the field, zero people survive blunt trauma. But the surgeons still go to the operating room, blood pushed in, time of death reported, blue gowns stretched. No heart beat means death, but he’s young. In the trauma bay, there are seconds to decide. So what do we do in the discrepancies of practice? The resident answered as my fingers slipped through the string while I tied the suture, “Do it right the first time and you won’t have feedback to change.” What is right then?

During a week of shadowing a family physician in rural Western Massachusetts, I met many patients who used alternative medicine, each one of them creating an understanding of health for themselves. We met an 81-year-old man named Charlie after he had finally undergone a hip replacement. His knees ballooned with swelling because he hadn’t been moving since his surgery. The family physician coordinated a surgeon who would operate despite Charlie’s self-administering antibiotics for 20 years for “chronic Lyme.”

“My chronic lyme has caused impotence…for 15 years, I haven’t had sex.” Charlie yelled into the wooden panels. “The other doctors don’t believe me…they think I don’t have lyme.” He repeated, enlarging his shoulders.

“They’re right… but moving will help the swelling in your legs.” the doctor said under the rumble.

The tug of war held with Charlie leaving the exam table and the doctor walking towards the door. Charlie placed his crutch as the doctor held the orange upholstered chair. The tug of war rope thinned as Charlie pushed his swollen leg into his car. With an expectant gaze, his eyes directed me to close the door. The rope fell as the metal door clicked shut; remaining closed until the next visit. The family doctor used protocol to set a standard of care as he explained lyme disease and accommodated with the patient’s preconceived notions of disease. However, at each visit, the doctor skillfully altered his approach to sustain the doctor-patient relationship; sometimes succeeding with Charlie thanking him and sometimes feeling inadequate like this last visit.

Even with protocols and best practices, patients own their health and care. For my father, the diagnosis landed without meaning until the numbers went bad. The teenage boy died before he
made it to the hospital. The man in rural Massachusetts trusted his own research over his
doctor’s. Protocols forget the patient; the person who lives with the decisions and changes within
a context of families and community. “We do our job on our side by explaining the outcomes
and risks, and the patient does theirs by choosing,” a nurse reminded me after a patient with
diabetes and a perianal abscess refused to change his wound dressing. I began, “I am hopeful
he’ll…” but I noticed wrinkled foreheads. “We’ll see,” I reframed and our team coordinated the
next discharge.