

# **Ghiso Fellowship Final Report**

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## **Introduction**

A few weeks ago at a pediatrics residency interview, I was asked, “It seems like you have had an incredible year, but I’m curious: how did you end up deciding to take a year off to learn more about palliative care?” I struggled a bit to answer her, afraid the order of events would make me sound unfocused, but I had to be truthful. In July 2006, I decided to take an extra year of medical school. At the time, I could explicate several reasons for the additional semesters—more time with my elderly grandparents, a chance to learn more about international health, an opportunity to do some writing—but there seemed to be something underlying that I couldn’t quite express. A month later I had an experience with a dying patient that gave me pause. Fortuitously, as I was trying to process that event, I opened up the email from Jeannie Hess about this fellowship. Everything clicked. My feelings of unease had stemmed from this issue: I was educationally prepared to be a doctor, but I didn’t know anything about death. Palliative care was the theme that tied together everything I wanted to do and learn during my fifth year; I had just needed a little more time to identify it.

## **Part I: Pain and Palliative Care Clerkship—Boston**

I started my year as a Ghiso Fellow by rotating on the Brigham/Dana Farber pain and palliative care service. There I learned the clinical nuts-and-bolts of palliative care: how to calculate morphine equivalents when dosing narcotics, how to arrange and conduct a family meeting, and how to push just a little bit to help families and patients reach the next level of understanding. While I didn’t do much formal writing, I did a presentation on a paper by Rita Charon about narrative medicine, which influenced my thinking about the stories we hear and tell in medicine. (I’m attaching the essay I wrote as the basis of my talk at the end of the appendix.) The month became my yardstick for the year; I was able to compare other experiences to how palliative care occurs in a tertiary care hospital in Boston.

## **Part II: Urban Primary Care Clinic—Santiago, Chile**

In what could only be described as a series of unfortunate events, I ended up spending my first month in Chile living in the basement room of a dilapidated downtown apartment (which the house cat confused with his litterbox) and working at an urban clinic. I also discovered that Chilean Spanish bears little resemblance to the Latin American dialect I had been taught. So my first month in South America was not what I expected, but I learned a tremendous amount (the first lesson of which was to keep my door shut at all times). Since I understood only my name in Chilean Spanish, my clinical experiences

those first few weeks were lacking in richness, but with the quantity of language practice, it served as excellent preparation for my second month in Chile.

### **Part III: Rural Primary Care Clinic—San Manuel, Chile**

I spent my second month based in Melipilla, a community of 95,000 people one hour south of Santiago. The Health Department of Melipilla funds two *consultorios* (primary care clinics) to serve the rural areas outside the city, and I was placed at the Consultorio San Manuel, which serves a population of approximately 7000 people, primarily scattered on small farms or plots of land throughout the area. I worked with a group of final-year medical students from the Universidad de Chile who were spending a month in San Manuel as part of a rural clerkship. We had a number of responsibilities in the consultorio—seeing clinic patients, creating educational programs on basic health topics, doing health screens at regional elementary schools, and going on home visits to

chronically ill and patients in the area (called *Programa Vida*). Programa Vida, while serving mainly chronic rather than explicitly end-of-life patients, provided treatment focusing on comfort and quality of life. Every Vida day, we would gather medications and food from the clinic for each patient, and then be driven by the clinic van to their homes. While some of the houses were reasonably nice, others were indescribably filthy, lacking running water or other basic services. At times, the degree of poverty was hard to

stomach. We would see the patient, do an interval history and exam, and give them the medications, making changes as necessary. Afterwards, we would write up a report for the chart with recommendations for the next month's group. It was gratifying to provide good, thoughtful care to individuals who otherwise would likely not have had access to treatment. I am attaching two pieces that arose from Programa Vida visits.

### **Part IV: Rural Hospital—Tobati, Paraguay**

Living in Tobati was an education: first, because there was only one other English speaker in the town (Vincent, a fellow American who wanted nothing to do with me) and second, because they gave me so much responsibility. It's one thing to be heavily supervised in a clinic, presenting to the attending before determining a treatment course. It is very different to be prescribing

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medication independently for the first time, and doing so in Spanish—at times, it was overwhelming. The clinic was staffed part-time with pediatricians, obstetricians, and an internist; each took turns covering emergency cases from all three services in the afternoons. I worked initially with the internist, but was uncomfortable with the care he provided his patients, so I focused on pediatrics for my time in Tobati. Unfortunately, this emphasis limited my exposure to death and dying issues in Paraguay. Additionally, our hospital, with capacity to treat overnight only obstetric patients, was not the clinic of choice for serious illnesses. However, I gladly passed four weeks in Tobati,

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seeing children with the pediatrician in the morning and on my own in the afternoon. My favorite case was a two-year-old boy who came in with a bean up his nose. I had never extracted anything from a nose before, but the nurses found me some tweezers, the mom put the kiddo in a headlock, and I successfully dug out the bean. It was very satisfying.

For several days in Tobati, I joined the vaccination team—nurses and public health educator who would be driven out into the surrounding rural areas and then walk door-to-door administering vaccines. It was quite an experience to see people living their daily lives, often in unbelievable poverty. Little girls tied together branches for a broom. Men made by hand bricks using clay dug from the ground with a horse-driven drill. Pablo, one of the nurses, and I were chased through a field by a rather grumpy bull, and then we watched a wizened old man grab the bull by its ring and lead him through the pasture like a docile calf.

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## **Part V: Hands of Hope Hospice—St. Joseph, Missouri**

During the summer, I spent six weeks working intermittently with the main hospice in my hometown of 70,000 people, which provides care to patients at home and in nursing facilities. I spent several half-days with the hospice medical director, rounding on patients in nursing homes. However, I spent a majority of my time with social workers and chaplains, which provided me insight into how different members of the hospice

team consider cases. We had one pediatric patient, the infant of a family of Spanish-speaking non-documented workers. With my interest in pediatrics and Spanish skills, the hospice team asked if I would accompany the mother and baby on a visit to the pediatric ophthalmologist to act as a translator. I am including a vignette about the experience.

The only true longitudinal case I saw during my year was in Missouri. During my first week with the service, I visited a lovely farmer at his house in the country. He was wearing pressed blue jeans and sitting in his rocker in the sunroom. His wife, to whom he referred exclusively as “Mother,” leaned on the back of his chair and smiled down beatifically as he regaled us with funny tales about a milk-stealing cat and their wedding. (He claimed that she poked him with a hat pin, and the preacher took his resulting yelp as an assent.) Six weeks later, we returned. He was in bed, face gaunt, too weak to sit. He tried to converse with us, the impulse to be polite unchanged, but it was too physically and mentally taxing, and he fell asleep only minutes into our visit. The change was striking.

### **Part VI: Pediatric Advanced Care Team—Children’s Hospital, Boston**

As I spent more time thinking about palliative care issues, I became interested in finding out how what I had learned applied in pediatrics. I arranged to spend one month with the palliative care team at Children’s Hospital, which was an incredible experience. I learned how to interact with families in a sensitive yet straightforward way about making decisions that are consistent with the goals they have for their children. I was also fortunate to attend the annual Ethics Committee educational retreat during my month, which gave me additional background in how ethics consultants think about palliative care cases. I am attaching two pieces from my time with PACT, one about an ethically complex situation with an adolescent and the other about a little boy close to death.

### **Part VII: McCord Hospital—Durban, South Africa**

It is difficult to know how to summarize my month at McCord Hospital; the experience was incredible and powerful and emotionally overwhelming. I spent one week in the pediatrics outpatient AIDS clinic. These children were on ARVs and doing fairly well. The other three weeks, I was on the female medical ward, a floor of approximately fifty patients, many of whom were dying of AIDS-related illnesses. While the hospital was very good and the staff dedicated, resources were tight and young women died every day. The hospital owned one ventilator, to be used only for cases with good enough prognoses to

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warrant transfer to other facilities; we didn’t see a single case during my month that fit the criteria. A significant number of patients we treated on the floor would be in ICUs in

the United States. And the nurses were not skilled at recognizing distress. Often we would be rounding and two hours after we had begun, we would find the woman in bed 22 gasping for breath. The nurse would confirm that she had looked that way since the early morning. It was heartbreaking. I am including two essays about patients I met on the female medical ward.

### **Part VIII and IX (future): PACT and Ethics research; Peking Union Medical College—Beijing, China**

Even though my year as a Fellow has drawn to a close, my projects have not stopped. I am currently spending a month doing research in the intersection between ethics and palliative care at Children's. During this month, Dr. Tamara Vesel and I are planning to put together a collaborative piece based on my essay, "The ICU," presenting the viewpoints of the medical student and the attending which we will then attempt to publish. This spring I am also spending two months in the spring as an exchange student at Peking Union Medical College in Beijing, where I hope to learn more about palliative care in China.

### **Reflections**

I had two main goals for my time as a Ghiso Fellow: to compare the approaches to palliative care in disparate settings and to gain confidence in my skills handling death and dying issues.

In terms of the first, the most prominent contrasts were between my domestic experiences in care of adults—the inpatient service in Boston and the private hospice in Missouri. It surprised me on the Boston service how much conversation among the medical professionals centered around identifying and promoting "work," on the part of patients and families. For example, in the hall after moderating an intense conversation between family members, the fellow would comment, "They did a nice piece of work today." It wasn't the language that caught my attention as much as the implication that the team had specific objectives for the patient and family. This style was very much in contrast to my experiences in Northwest Missouri, where practitioners seemed to consider themselves open receptacles, ready to hear what the patient wanted to offer on the patient's own terms. (And if they did have an agenda, it did not necessarily promote work on the patient's part. I watched a heartbreaking exchange between patient and nurse where he started to tell a story about atrocities he witnessed during World War II and the nurse cut him off to ask about bowel habits.) Perhaps the difference was one of discipline—doctors and nurse practitioners versus social workers and chaplains—but my guess is that the nature of a teaching hospital or the differences between inpatient and outpatient care had more to do with it.

One clear way the pediatric service differed from the adults was that many of the patients are followed for years. The team typically is introduced at a crisis point to help with

decision-making, and then will be in contact with the family throughout the child's course. When the child is healthier, the team maintains infrequent social contact. But then when the child has a subsequent episode, the relationships are in place for the palliative care team to be an even better source of support for the child and family.

I found it more difficult to draw conclusions about palliative care from my time in South America because I was not rotating with dedicated palliative care services. From informal conversations with my colleagues in Chile I learned that terminal diagnoses are often discussed with the family rather than the patient. Not infrequently, the family feels the information should be concealed from the patient. I saw similar paternalism in action when I watched the initial discovery of an almost certain tongue cancer. The patient was only told that she should see a surgeon about having the "spot" removed. Feeling it would cause her worry, no one mentioned to her the possibility that it might be something serious. In Paraguay, I did not have enough contact with death and dying issues to make specific comments, but my general sense suggested that they also practice with a greater degree of paternalism than is common in the United States.

I don't know yet how to describe all that I learned in South Africa. The magnitude of the AIDS crisis is boggling—despite my book knowledge of the epidemic, I was absolutely unprepared for what we saw. In some regions of South Africa, the prevalence of AIDS is over 60%. A study is underway in the mountains near Durban to HIV test all babies born at the center: the preliminary data shows that about 50% of the babies are positive. However shocking the numbers, the sight of a ward filled with women my own age close to death stopped me cold. And on the wards there simply wasn't the time to address issues of death and dying; we were too busy putting in central lines and managing airways. At a lunch conference, one of the head doctors, a kind-hearted and dedicated palliative care specialist, told us that we should consider patients for compassionate care at admission based on diagnosis (e.g., someone with stage four AIDS should not receive antibiotics.) We simply could not afford to use our limited resources for patients without a reasonable likelihood of survival.

As for my confidence handling death and dying issues, this year has made a big difference. Watching many interactions between patients and seasoned clinicians has provided me with a mental model for the type of practitioner I want to be. And I have had multiple opportunities to start honing my own skills—my personal statement for residency centered around my interaction with the Spanish-speaking mother in Missouri. Most importantly, I am now tuned in to palliative care issues when they arise. One afternoon in Durban, we decided not to intubate a dying woman. As the team milled around lost in our own thoughts, I remembered that her family was in the conference room. We were able to bring them to her bedside for her final breaths. Although it did not lessen the pain of losing her, at least her mother knew that the woman's last moments were peaceful.

## **Acknowledgments**

My experiences as a Ghiso Fellow were amazing. I would not have changed a single part about the year (except, perhaps, choose a cat-free apartment in Santiago). Not everything turned out as I had expected, of course. The most prominent example was my hope for specific palliative care exposure in South America. But I discovered that it is extremely difficult to coordinate nuanced electives abroad, and I'm not sure that I could accomplish it now, even with personal contacts in South American hospitals.

Dr. Jim Sabin was an excellent mentor with spot-on suggestions about my writing. Dr. Bob Buxbaum was ready with advice whenever I asked. The individuals who helped me coordinate electives could not have been kinder or more accommodating: Dr. John Peteet at DFCI, Dr. Klaus Puschel in Santiago, Professora Therese Milan in San Manuel, Andrini Ayala in Tobati, Jim Pierce in St. Joseph, Dr. Tamara Vesel at Children's, and Dr. Henry Sunpath in Durban. Kari Hannibal was extremely helpful with international electives, and Jeannie Hess was very generous with her time during the planning process. The help from many others along the way has reminded me how much kindness there is in the world. I am so grateful to the Ghiso Foundation for the opportunity to spend a year trying to learn about death and dying. I still have many lessons ahead, but I'm not so afraid anymore.

## **Appendix**

Although names and identifying details have been omitted from these pieces, I would prefer not to have them widely distributed without my knowledge. Thank you.

1. The Sisters
2. The Catheter
3. Baby Hannah
4. The ICU
5. Conversations
6. Two Women
7. A Death
8. Narrative Medicine Talk

## **The Sisters**

### **San Manuel, April 2007**

The sisters' house was small and tidy, with a front path lined by rosebushes. Tiled floors, polished wood dining room set—almost extravagant compared to their neighbors. However, the simple bedrooms and kitchen depicted poverty just under the surface. The younger sister, somewhat unsteady despite a crutch because her hips listed to the left and her shoulders to the right, lead us to the bedroom. There in an iron bed was her sister, round rosy-cheeked and smiling. She greeted us warmly. Both hands had fingers maybe 1-inch long, almost as if the digits had collapsed into her palms—the effect of longstanding rheumatoid arthritis. The result was a small, wizened hand that she moved as if there were no bones left—she could push the bedcovers away, but most of the resistance came from her wrists. Her hands had been reduced to meaty appendages.

They both reported no new complaints since the previous visit. Their exams were unchanged from the record of the last. A puppy—all ribs and elbows—played under the bed, occasionally whining for attention. We stayed and chatted for a long while; there was no need to hurry today.

Eventually we went outside to wait for the clinic van. There were chickens in the front yard, including several roosters strutting through the roses. The side yard was an animal pen of sorts, entirely barren of grass. A few more malnourished puppies wandered through—one gnawed listlessly at a dry bone. Towards the back of the side yard was a pen made from wooden boards and chicken wire. We could hear the two small pigs better than we could see them. The younger sister opened a gate at the back—a crew of sheep darted into an attached field. My partner, Daniel, asked how she would gather the sheep at the end of the night—“They come when I call them,” was her reply.

The weather was perfect. We sat on the porch and listened to the animals. Occasionally there would be wind in the trees. Across the street was a beautiful view of the mountains. The world seemed so quiet.

## **The Catheter**

**April 2007, San Manuel**

The place was easier to reach than some, just off the main road and down dirt road. We parked in front of someone else's gate and walked through several barren yards to reach the yellow clapboard house. A young man with foreshortened arms in a wheelchair, presumably the son, was playing an old-school Nintendo game in the front room. The patient's wife, who had such a large Dowager's hump that she was bent in half, showed us to Jaicinte's bedroom.

His right eye was cloudy blue with a cataract; the right was brown, but out-of-focus—I had a hard time knowing how well he could see. A lack of dentures made his Chilean Spanish impossible for me to understand; I was glad to have Daniel, the Chilean intern, with me. Our patient was sitting on the edge of the bed, wearing grey sweatpants and a button-down flannel shirt. The room was clean and smelled only slightly of urine, much better than most. When we came into the room, he smiled briefly, and started carefully unwinding the string that connected the urine collection bag to his sweats. As we set down our tackle-boxes of supplies, he took off his pants and lay on the bed, ready for us to proceed.

I changed into a clean pair of gloves. We had washed our hands thoroughly at the clinic before coming, not knowing if the house would have running water or a clean enough bathroom for us to enter. We had each worn a pair of non-sterile gloves for the ride over, to keep the semblance of cleanliness. Daniel pulled a chair to the bedside for me and handed me an empty needleless syringe to deflate the water-filled balloon that was keeping the catheter inside Jaicinte's bladder. The waterport was grimy, and the syringe wouldn't attach properly. After several minutes of struggling, I gave the syringe to Daniel, who said, "Well, maybe it will work better with a needle on." He was successful, and I removed the old catheter from our now-cringing patient.

Next on the list was to prepare our sterile field. I put on the sterile gloves. Daniel handed me some sterile gauze and proceeded to pour isopropyl alcohol on it (from his personal supply—the clinic doesn't stock iodine and we couldn't find alcohol). I started to clean the area, but was struggling with only one hand because I didn't want to contaminate my gloves. Eventually, Daniel opened a big piece of gauze, which we doused with alcohol and sterile water, and this worked better. The clinic was also out of sterile drapes, so I was focused on cutting a hole in another piece of gauze with sterile scissors, when Daniel noticed that flies had contaminated everything I just finished cleaning. We did the best we could with some more gauze and alcohol. The patient still lay quietly.

The insertion of the catheter went more smoothly—Daniel had brought some lidocaine jelly, which made the patient much more comfortable. However, the clinic was out of the tubing to attach the leg back to the catheter, so rather than reuse the month-old tubing and risk introducing infection into the new apparatus, I attached the leg bag directly to the catheter and then strapped it to his thigh, much to the patient's displeasure. We assured him that he would be able to buy more tubing tomorrow in Melipilla—his wife had told us that this expense was possible for them. I am still unsure exactly how they're going to accomplish inserting tubing between the catheter and leg bag with everything in place, but I am hopeful that necessity will breed creativity.

We gave the man and his wife flu shots on our way out. It had been a while since my last shot, and I forgot to draw back to make sure I hadn't hit an artery before pushing the plunger. The wife appeared no worse for my lapse, but all the way down the road, I imagined the terrible implications of an air embolus as well as the risk of infection we had created for the man.

While it is easy to focus on what Daniel and I didn't have available, and how a five-minute procedure can stretch into forty-five minutes with improper equipment, I am still struck mostly by how fortunate Chile is to have a system that allows us to go to people's home and help. There are few other developing nations that would dispatch medical students with enough equipment to successfully change a chronic catheter, or even deem an elderly man with a too-large prostate important enough to receive a catheter at all. In the United States, we spend a lot of time focused on providing "optimal care," and sometimes lose sight of the people who receive no care because of our obsession with perfection. Perhaps the Chileans (and Harry Truman) have it right, doing what they can with what they have where they are.

**Baby Hannah**  
**June 2007, St. Joseph**

How do you ask someone about the interventions she would consider for her dying baby? Now quickly and in Spanish, too.

Robbed of my euphemisms, my ability to soften difficult questions limited by vocabulary memorized from lists, I was stumped.

"What are the plans for Hannah?" I asked as gently as I could. I watched Mary's sad eyes move downwards to the baby in her arms. Hannah's features were a bit off—short-socketed eyes closely set in a small head, and she breathed with the constant juicy whistle of small nostrils partially filled with fluid. But the calm, practiced way Mary sat her up and caught milky vomit, and the coos she whispered to a baby who could not hear them belied the truth: Hannah was cherished. And it was clear that despite her acceptance of hospice services, Mary did not truly believe the doctors' grim prognosis for her baby with trisomy 13.

I tried to backpedal. "The doctor is asking if you would consider surgery if it would help Hannah see better or do you only want to have medications?" Although the classes in conducting my own medical interviews were helpful, this role of translator was new and rather awkward.

Mary's still downcast eyes met mine briefly. "Anything that will help her," she quietly responded.

The medical economics side of me wondered if any of this made sense. How much would Hannah's life actually be improved by a clunky hearing aid and four-month-old size goggle-glasses? But sitting with Mary, the cynic receded. I knew that if Hannah were mine, I would not ask for anything less. It's her baby. My ability to rattle off the grim prognosis for Patau's syndrome will never dampen Mary's hope that somehow her baby might be different.

## **The ICU**

### **September 2007, Boston**

Her eyes were ringed with dark circles, exhaustion and desperation written in her expression and wan complexion. The old-fashioned dark-colored dress sprinkled with somber flowers was on its third day's wear. She appeared so fragile, so physically and emotionally overwrought, that I thought she might pitch over at any moment. I was glad she had a steadying hand on the "Caution: Wet Floor" sign in the doorway of her son's ICU room.

The husband wore glasses with one eye blacked out to hide the eye he had lost to a tumor in childhood. He was decidedly upbeat, overcompensating for his wife's moroseness, as if a moment of solemnity from him might push her over the edge. Who could blame him after she had accused him of placing a hex on their child when a what-if question he posed the week before came true? He bubbled to the team, "When I came this morning and spoke to Clarence, his head nodded at me. I spoke again and it didn't move. But I still think he was greeting me." He nodded his own head vigorously at the memory.

Our discussion was brief. The father mentioned again the falling white count as a sign that the leukemia was getting better, that their prayers were being answered. My attending sighed and tried to gently say we were afraid that it was more the infection than the chemotherapy that was causing the drop in numbers, but she didn't push as hard this morning as on other days. We were all weary from the long campaign for the parents to stop aggressive interventions, to allow Clarence to die. The mother responded that she was concerned he might be constipated. The father told us again how when Clarence awoke after an ICU stay several months before, he had said he felt joyful to be alive.

The husband took up his near the head of Clarence's bed; he sang a morning song to Clarence with the help of a wild-haired lion puppet. The puffy-faced, intubated six-year-old lay motionless, arms and legs splayed on pillows, his belly more distended than yesterday. The futility of our battle to keep him alive was becoming ever clearer, but his parents' staunch insistence that a miracle was soon-to-come kept the tube in place and the antibiotics flowing. I didn't know whether to hope with them for divine intervention or to hope that Clarence would just give up on his own. I was grateful for Clarence's sake that either way, the end would be soon.

## Conversations September 2007, Boston

### **Part One:**

The first thing I noticed about the mother was her sharpness—her angular face, biting humor, the occasional edginess directed at her husband. Except for an aura of frenetic energy, nothing in her demeanor suggested that her teenage son lay dying down the hall. She was focused and direct, “We only have twenty minutes. He gets nervous whenever we’re gone talking to doctors for very long.” All four of the palliative care team members sat up straighter in our chairs.

The husband tried to be conciliatory, although he also appeared not entirely comfortable with the involvement of the pediatric palliative care service in his son’s care. “We’re a little confused about your role in all of this,” he said.

The meeting proceeded more smoothly than I had anticipated given the start, and both parents seemed to relax after our attending mentioned that one of the many ways our team could be helpful was in end-of-life issues. It was as if they had thought we were planning a sneak attack—infiltrating their defenses with ideas for symptom control only later to unveil our agenda about their son’s death. But being upfront about death from the beginning somehow allayed their fears.

Although they remained guarded, we saw glimpses of their competing realities. When asked to describe his son, the father said, “He’s gregarious. Life of the party. I think he’s headed for a career in sales.”

She snapped, “No, he’s going to die.”

### **Part Two:**

We saw them again several days later in the son’s room. His condition had further deteriorated over the weekend, and his steroid myopathy was now so bad that he could not use the remote control independently. He sat up in bed, face swollen, limbs atrophied, suction catheter for secretions draped over one shoulder.

The primary team was concerned. His parents had stated that as his health care proxies, they did not intend to allow intubation. But they were very reluctant to discuss the situation with their learning-disabled nineteen-year-old. “He’s a fighter,” they kept repeating. “This news will devastate him. Do you want to completely ruin his final days?”

The primary oncologist had agreed. “He is unable to understand the concept that he might die. It is outside the realm of possibility in his mind; he’s a very concrete thinker. I think that even if we tried to explain everything to him, he would be unable to make an informed decision.”

The palliative care attending and I chatted with the family and patient at the bedside. The attending asked the patient, “Tell us. Say that in the middle of the night you were not able to speak for yourself. Would you be comfortable letting your parents make decisions for you?” The mother, standing in the corner, visibly bristled.

The son looked at us directly, and said in a halting, garbled, mouth-full-of-rocks voice, “Yes. But I want to know everything.”

### **Part Three:**

A meeting was called for the following afternoon. All of us gathered in a small conference room—the parents and an aunt, the primary oncologist, the floor attending, the palliative care team. The atmosphere was tense and anxious; it felt like a strategic planning session for a battle. Down the hall, the patient was watching *The Simpsons* with his favorite nurse.

The meeting opened with discussion continued from the day before about the DNI order. The parents were definitive; no one was to tell him about his prognosis. The primary oncologist reiterated his belief that the patient was too limited to understand such information anyway. The plan for a life-threatening event was restated: supportive care until the patient's condition warranted the invocation of the proxy. Then the parents would sign a DNR/DNI.

The floor attending voiced her discomfort with denying information to a nineteen-year-old; she said that if the patient remained in the hospital, someone would have to have a more direct conversation with him.

The palliative care attending volunteered that she had found a hospice willing to provide twenty-four hour home care beginning the following afternoon. A quick discharge would allow the family to celebrate an upcoming religious holiday together at home.

A lengthy discussion followed about how best to ensure that the patient would not discover he was going home to die. Elaborate plans were developed to control communication around this issue with the patient.

Finally, the palliative care attending spoke. She said quietly, "I just don't think you can not tell him. If you don't tell him here, someone from hospice will have the conversation. It is not possible for them to be involved without his knowledge and consent. Do you really want it to be a hospice nurse? Wouldn't it be better coming from people he knows and trusts?"

The room was still; the frantic, emotionally charged conversation stopped. The mother cried quietly into a tissue. She had been the most fervently opposed; we waited for her reaction.

"I can't. I just can't. He's my son. How do you tell a nineteen-year-old that he doesn't have a whole life ahead of him? That he's going to die. Not in eighty years, like he thinks, but now, this week, maybe tomorrow. It's not fair." She sobbed, harsh, guttural cries from somewhere deep and sacred. I couldn't breathe.

We waited. Her cries slowed and she looked up with resignation in her tired eyes. "You say it must be done. We have to do it, then. It has to be us. I can't let it be someone else."

The conversation happened in the early evening with just the parents and the primary oncologist. It was tearful and hard, but in the end, the patient agreed that he did not want to be intubated.

### **Part Four:**

The next morning, the attending and I made a social visit. The curtains were open and the room filled with light. The father was fluffing his son's pillow. Though worries still etched her face, the mother was smiling. It was as if the elephant in the room now

sat quietly in the corner, present but no longer the center of attention. The family told us how excited they were to go home.

**Coda:**

The family had a great week. On the evening of discharge, the extended family, including the patient's college-age brother, gathered at the house for a holiday meal. The patient sat at the head of the table. He died at home the following week, both of his parents by his side.

## **Two Women**

### **October 2007, Durban**

She was our nineteenth patient on rounds, and when we got to her bedside, I couldn't imagine that someone would not have brought her to our attention sooner. I knew the South African hospital was overloaded, but this was too much. She was an older woman breathing rapidly and deeply, her head thrown backward, mouth slack with drawn lips exposing her teeth and gums. We tried to get her attention, but her eyes were unfocused, the right fixed in the inner corner, and the left rhythmically tracking side-to-side. Her pupils were unresponsive to my small flashlight.

The overnight intern thought she had had a stroke and that heart failure was causing the respiratory issues. So he gave her a diuretic and her home meds and then left her for the morning team to sort out. We picked up the labs ordered hours before and knew immediately that she was floridly septic. A diuretic was the worst possible choice for her; she needed liters of fluids as quickly as possible.

Our team immediately cleaved with the medical officer, the South African equivalent of a senior resident, and me remaining behind. Gloria automatically went to work to secure IV access in a major vein, but the woman's veins had all collapsed, and she kept hitting arteries. I tried to take vitals, but the woman didn't have pulses in her arms or legs, and I couldn't convince myself that the nearly imperceptible bobbing of the needle on the blood pressure cuff was real. Thirty minutes later, the woman had two small lines in her neck, but we had made no real progress.

Gloria and I were joined by David, a visiting resident from Boston. The two of them continued the quest for central venous access, making repeated attempts to place lines in the femoral arteries and the subclavians. We were told there were no more line kits, so they started rinsing out their needles with antiseptics before going back in. Each time they hit an artery we would all pause, watching the catheter intensely for pulsating blood. The normal red gush of an arterial stick had given way in this patient to a dark red intermittent pooling at the catheter's head.

A nurse told us the family had been notified of her worsening condition; they requested that we write a letter so the woman would be finally responsible for her own hospitalization. Gloria was angry at this callous response. I held a fluid bag in each hand, trying to squeeze the fluids in faster. When David suggested starting pressors, one of the interns responded, "What's the point? Even if we pulled her through, her prognosis is guarded at best."

Finally an attending from the "high care unit" arrived to help us. She was able to place a subclavian line. Moments later, blood started gushing from the woman's mouth. I jumped from my place anchoring the woman's head to make space for what I thought was a certain intubation. At the same instant, David said he had lost the femoral pulse; this was the time to start chest compressions. The attending looked at Gloria and said, "It's your call."

Gloria looked at us and shook her head slowly. As the precious seconds ticked by, all of us stood near the bedside discussing the case. Soon two nurses came over and began to lay out the body. I don't remember anyone pronouncing her dead. I never even heard her name.

When I returned to that bay of beds an hour later, the body was gone, but David was back in bedspace 16 with a tube draining fluid from the side of a young woman. He pulled off about two liters of a pink liquid from between her lung and chest wall. Her eyes had a frantic look as she sucked oxygen from her mask. Her purple satin nightgown was damp--she had so much extra fluid that the skin on her breasts had cracked and liquid was oozing out in all directions. Her stomach was tense and distended, and the profiles of her feet lost in the swelling.

She had arrived on our ward two days before. She was eighteen with a two-year-old daughter and newly diagnosed AIDS. She had liver failure, we thought maybe from abdominal tuberculosis, and her body could not handle its own fluids.

David and I packed up samples of the pink liquid in tubes, hoping the lab would diagnose TB so we could start treatment. The woman started breathing faster and moaning; David called for a stat chest x-ray and put her on her left side. The x-ray did not show a punctured lung, but the new position still eased her breathing.

Her mother and young daughter came in for an unscheduled visit, but we were trying to put a catheter in the woman's bladder to make sure she was still making urine, so it was not possible for them to stay. As a nurse led them down the hall, the daughter's screams echoed down the hall. Visiting hours are strict here; I am not sure if they were able to return.

We were called back to her side a bit later because her breathing had deteriorated again. But this time was worse; her eyes were cocked at odd angles, and she was not responsive. David called for a blood sugar test; hers was very low. Two of the nurses tried to put dextrose through her partially infiltrated IV line; the syringe popped off the valve under pressure and we were all sprayed with sugar water. With all the South African residents off the floor, David and I began the interesting process of trying to order stat glucagon in a foreign hospital. Fortunately, one of the head nurses was able to finesse the IV, and our patient awoke. She appeared comfortable.

Our long day was over soon after, and David prepped the on-call intern for possible problems overnight. But the next morning, when we came in, bedspace 16 was empty.

Our eighteen-year-old patient had died. The on-call intern said she had been called to the bedside for respiratory distress, but when she arrived, the patient had passed. There was no fanfare; no code; no emergency intubation. Just a pair of nurses to lay out her body. But this time, I knew this woman's name. Her name was Joy.

## **A Death**

### **October 2007, Durban**

I killed my first patient today. I know that every doctor carries in his psyche a graveyard, but I wasn't ready to put up my first tombstone.

She was really sick. Came into the ward face down on a stretcher—that's always a bad sign. The resident said, "Kate, you take this one. Lulu and I are going to the boiler room to work on discharges."

While the nurses were getting her undressed, I read through the chart. A forty-year-old woman with AIDS, diagnosed one month ago. Went to a hospital three days ago because of a fever and headache over the weekend. They did a spinal tap for likely meningitis, but she didn't have the money to pay for admission, so they sent her home. I am not sure why the family did not choose to take her to a public hospital where she would have been guaranteed to receive care.

She was seen yesterday in our outpatient clinic. The doctors there agreed that it was likely meningitis, but she again could not pay, so they suggested that she return today with the results from the spinal tap.

This morning, she awoke unable to speak, according to her mother. When her family returned to the clinic with her today, her level of acuity was such that the hospital could not turn her away and she came to our ward. The results on her paper read "cryptococcal meningitis," a devastating fungal infection in the cerebrospinal fluid.

I finished gathering history from her mother and turned to the exam. She was sleeping, but arousable, and when her sister spoke, she tried to respond, but could not get words out. Her hair was sticking out at odd angles, and her face marked with healing chicken pox from the week before. Her vital signs were stable. As I hurriedly gathered my papers to take downstairs, I saw one of the nurses at the bedside with a plate of food and a spoon.

I presented her to the rest of the team and late for a meeting, hurried from the hospital. Two hours later, I was back on the floor eating mutton curry in the small conference room. As I closed the styrofoam takeaway box, a flustered nurse came into the room.

"Bed 15, she is breathing funny. I think you should come." The residents and I left at once.

Her breathing was strained and ragged through her open mouth. Grains of rice mixed with blood and mucous clung to her chin and gown. We sat her up in bed; She was limp and unresponsive. David pulled her eyes open; her pupils were big and did not change with my flashlight shining in. Her vital signs were still stable.

David drew a blood gas, and I ran downstairs to feed the sample into the machine in the intensive care unit. The numbers weren't as bad as we expected. The suction machine had finally reached her bedside, and they were trying to attach the tubing.

I called down for an urgent chest x-ray and EKG. The South Africans laughed at the urgency in my voice, but reluctantly agreed to come—apparently the best way to get the techs to the floor is an American accent.

Back at the bedside, our patient was looking worse. Her respiratory rate had slowed further. David said that this was our decision point—were we going to intubate her or not? We all looked at each other; the answer was clear.

We brought the family to the bedside. The sister was dazed; the mother only looked weary. The mother closed her eyes as she placed her hand on our patient's forehead.

David felt for a pulse. He looked up at me, and I put my stethoscope on her chest. Her skin was warm, but she sounded strangely hollow. I turned the knob on my stethoscope, but it hadn't been wrong; there was no heartbeat. I looked at the mother and said, "I'm sorry."

She sighed. David offered that we could give them some time alone with the woman; they declined and after accepting our brief condolences, left.

We returned to the conference room drained. David said, "This should be a lesson for all of us: you should never feed an obtunded person."

It was like a punch in the gut. I went cold and numb. I had seen the nurse come with a plate. I should have stopped her. In Boston, I'm accustomed to nurses acting fairly independently and making good choices. Here the nurses, while kind and well-meaning, require more explicit instructions. I should have been watching more closely. I learned early in med school that you never give someone with altered mental status food. It is such a simple lesson; how could I have not noticed it?

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In the week that has now elapsed since I started this essay, the emotional has given way to the rational, and I have let go of some of this sense of responsibility. She was dying long before she came to our floor; end-stage AIDS and cryptococcal meningitis is a devastating combination and she was long past the point when treatment should have been started. Further, from her exam it was unclear if she worsened because of aspiration or because of brain herniation from her disease. And as David pointed out, if you die from aspirating one bite of food, you've got bigger problems than just the rice.

But there remains deep down in me the question: did my neglect to stop the nurse from picking up that spoon somehow hasten her death? I'll always wonder. It's funny in medicine: when the outcome is good, the team celebrates together; when things go poorly, you rack your brains for what you personally could have done differently. I guess it's good to be reminded every so often about how easy it is to make a mistake. I certainly will never forget this one.

**Narrative Medicine Talk**  
**January 2007, Boston**

**The Paper:**

*Narrative Medicine*

*A Model for Empathy, Reflection, Profession, and Trust*

Rita Charon, MD, PhD

*JAMA*. 2001;286:1897-1902.

**ABSTRACT**

*The effective practice of medicine requires narrative competence, that is, the ability to acknowledge, absorb, interpret, and act on the stories and plights of others. Medicine practiced with narrative competence, called narrative medicine, is proposed as a model for humane and effective medical practice. Adopting methods such as close reading of literature and reflective writing allows narrative medicine to examine and illuminate 4 of medicine's central narrative situations: physician and patient, physician and self, physician and colleagues, and physicians and society. With narrative competence, physicians can reach and join their patients in illness, recognize their own personal journeys through medicine, acknowledge kinship with and duties toward other health care professionals, and inaugurate consequential discourse with the public about health care. By bridging the divides that separate physicians from patients, themselves, colleagues, and society, narrative medicine offers fresh opportunities for respectful, empathic, and nourishing medical care.*

**To be read aloud:**

**Chapter 1: Why I like stories**

Some people are born story-tellers. My father is one—he can mesmerize the room with a tale that would sound mundane in the mouth of someone else. I thought about beginning today's talk by telling one of our family legends—"The lady who came to breakfast and stayed five years," "Why the cat vomit smelled like Old Spice"—but I'm afraid I can't live up to the exacting standards of delivery these stories demand. Unfortunately, my brother inherited the story-telling gene; I am more the appreciative audience type. But Rita Charon, the author of today's paper, would tell me that's okay.

**Chapter 2: Why I chose this paper**

I was an English major in college, so I spent a lot of time thinking about stories. Med school has been sort of my deconstructionist period—where I have learned to understand stories as an assortment of unruly facts requiring the formal presentation's structure to bring them to order. Any narrative, no matter how beautiful or poignant, can be reduced to a bullet. "A 72 yo man with end-stage COPD presents with rectal bleeding."

But I'm not really intending to complain. While not long on beauty, the bullet is in its own way quite evocative. Your mind's eye might not paint my rotund and tidy British patient, but my guess is the similarities between our mental pictures would be striking. There is a satisfaction that the efficiency and efficacy of medical communication affords. And I recognize that I'm still in my medical toddlerhood—the form must be fully absorbed before it can become invisible. That my story-telling on rounds is still clunky and awkward is not the fault of the format.

But there is a different problem with the form: it gives us the temptation to be lazy—to listen for the facts rather than for the story. I spend Wednesday afternoons tutoring second year med students in history and physical taking. And I admit that I feel secretly superior as I watch them scribble frantically to write every word the patient says. But what do I do now that obviates that need? I have a pre-fabricated storyline in my head, and I just listen for the keywords that let me pluck out the nuggets of data and plop them into their proper positions. It's certainly more efficient, but is it better?

As I have spent time on palliative care with all of you these past few weeks, I have seen in practice how the story can be more than just a fact-gathering mission. So when I was tootling around PubMed last week looking for a paper to present, I ran into this one, and it intrigued me.

### **Chapter 3: The Argument**

In Rita Charon's paper "Narrative Medicine: A Model for Empathy, Reflection, Profession, and Trust," she describes the importance of story-telling in medical practice. She describes *narrative competence* as, "the ability to listen to the narratives of the patient, grasp and honor their meanings and be moved to act on the patient's behalf." In her mind, it is the narrative that drives the relationship between doctor and patient. And when I picture the harried surgical intern finishing her twentieth post-op check (How's your pain? Any flatus yet?), I can see how she can make that argument. It's certainly not the paperwork that makes the job of a physician special.

I believe the heart of Charon's paper lies in her description of the narrative space that is created between the doctor and the patient. She writes, "...the meaning of a text arises from the ground between the writer and the reader, and that 'the reader . . . does quite half the labor.'" Thus, the responsibility for the story is shared. I think we easily lose sight of this in medicine. We have a naïve belief that the patient only has one story, and that we can write this story in the chart as objective fact. But story-telling doesn't work that way. As Lynne Freed describes in her book *Reading, Writing and Leaving Home: Life on the Page*, "The tale told must adjust itself to its audience. The teller must judge timing and response, cut as she speaks, leap, if necessary, whole segments, or flesh others out, to arrive at the denouement exactly on time." So, if the story is a unique and fluid entity created in the space between listener and teller, then we are unreasonable to expect perfect consistency from our patients. Perhaps this is the secret why medical students and attendings never get the same history.

Modeling the traditional descriptions of literary conflict taught in all American high schools (man vs. man, man vs. himself, man vs. society), Charon describes four manifestations of narrative medicine: Physician-Patient, Physician-Self, Physician-

Colleagues, and Physician-Society. I think it is worth considering each briefly, as time allows.

So first, Physician-Patient. The idea of narrative medicine in the patient-doctor relationship is relatively well-established. So I want to discuss specific quote from this section. She writes: "...the narrating of the patient's story is a therapeutically central act, because to find the words to contain the disorder and its attendant worries gives shape to and control over the chaos of illness." I find the idea that telling a story helps a person demystify his or her own experience compelling, but it seems too neat and tidy. The idea resonates with me in theory (it encompasses much of my own writing practice), but when I think about the experiences I've had so far this month, the times when I've seen patients make breakthroughs, it has been through probing questions not the narration of symptoms. (And perhaps I take Charon too literally.) What have been other people's experiences? Are there times when the story itself is enough?

Then we move to Physician-Self. Charon explores the role and power of narrative reflection by physicians. I didn't find any particularly compelling quotes to discuss, but my sense is that I'm in the presence of many who strongly believe in this. It seems like a necessary part of doing this work. I know I've struggled more than usual this month—my poor roommates have been very tolerant of my need to verbally vomit all of the terrible suffering I've witnessed during the course of my day immediately upon arriving home. I would love to hear ideas and thought on this.

And the last section I would like to discuss is Physician-Colleagues. Charon surprised me here. After several weeks with the Pain and Palliative Care team, I was anticipating this to be about group reflection and story-telling between professionals. But it's not. She brings up two distinct ideas: research as narrative and medical education as narrative. She writes, "Scientific research results from the muscular narrative thrust of first imagining and then testing scientific hypotheses. . ." And then her description of the education almost places the student in the role of the receptacle of an oral tradition: "The student becomes the physician by functioning as a medium for medicine's continuity of knowledge, learning about diseases in the process of living through their passages."

And the last, Physician-Society, which I think might be a bit of a stretch. She writes, "Only sophisticated narrative powers will lead to the conversations that society needs to have about its medical system. Physicians have to find ways to talk simply, honestly, and deeply with patients, families, other health care professionals, and citizens." Maybe she has a point somewhere in there, but I think it's buried in the rhetoric.

#### **Chapter 4: What Does All this Mean?**

So all this theory is well and good and I think palliative care physicians and psychosocial oncologists embody these traits as well as any two groups of doctors could, but isn't it difficult to achieve this all the time? I'm a great listener when a good storyteller takes the stage, but what about the patients who ramble and wander in circles? If we accept this idea that the listener is partially responsible for the quality of the narrative space, then we can't really blame the patients alone if their stories stink. So my question is, how do we as listeners help draw out the best and most important stories from our patients?