

# BJMH

The Brown Journal of Medical Humanities



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# Masthead



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In the spirit of a true medical journal, The Brown Journal of Medical Humanities borrows from medicine's highest ideals of patient intellectual honesty and an awareness of our biases and limitations. The Journal honors the legal and ethical standards of contemporary medical and academic journals. All submissions must adhere to the confidentiality guidelines explained in the Health Insurance Portability and Accountability Act (HIPAA) as well as the requirements of the Privacy Rule. We also urge authors to seek permission if submitting patient narratives and, if necessary, fictionalize and/or modify any identifiable personal information of subjects. Where necessary, editors have omitted or changed any potentially identifying information to protect patient confidentiality.

### **Disclaimer**

We seek to give voice to unheard experiences of illness, foster empathetic dialogue between patients, clinicians, and the caring communities, and create a sense of community between patients, clinicians, medical students, writers, artists, readers, and scholars. As such, we hope to be a platform for new voices, a proving ground for new ideas, and a forum for the difficult but necessary conversations to transform healthcare. However, the perspectives, thoughts, and opinions conveyed in any materials published by The Brown Journal of Medical Humanities belong solely to the author and do not represent those of The Brown Journal of Medical Humanities, the Cogut Institute for the Humanities, or Brown University. In addition, the information featured on our website or print journal is not to be interpreted as professional or medical advice by The Brown Journal of Medical Humanities, its authors, or any affiliates.

# Foreword

*Science sans conscience n'est que ruine de l'âme*  
[Science without conscience is but the ruin of the soul] —François Rabelais, *Pantagruel*

As the founding members of the *Brown Journal of Medical Humanities*, we are proud to present the inaugural issue of our publication. We are launching the journal during an unprecedented time of vast global changes, from the tragedy of the COVID-19 pandemic to the Russian invasion of Ukraine. As Brown's campus slowly revitalizes after a prolonged period of social distancing, we find ourselves in a place both familiar and unknown. Yet one thing remains certain: the power of stories to connect, inspire, and heal.

One of Brown's greatest treasures is the Open Curriculum. With greater freedom and flexibility to discover what we love and study what we choose, Brown's distinctive approach to learning enables students to become architects of their own education. It was this heightened responsibility to take ownership of our studies that inspired us to launch the *Brown Journal of Medical Humanities*.

Designed as a forum to process the grief, loss, and heartache sparked by the global pandemic, the journal is our response to the unexpected ways that COVID-19 has disrupted our lives. Moreover, we believe it can serve as a platform for discussion and means of connection amongst all shared experiences of health and illness. We understand medicine as a fundamentally creative act, with narratives and the arts as essential clinical skills for embracing the ambiguity and complexity at the heart of clinical decision-making. We believe firmly in the power of art and literature to heal, and we hope to provide a space for meaning-making and representations of experiences from all those involved in the medical encounter, patients and providers alike. It is with this in mind that we have featured a range of pieces in our inaugural issue, hoping to give voice to unheard experiences of illness and serve as a testing ground for new ideas.

With the spirit of both a medical journal and writer's collective, the *Brown Journal of Medical*

*Humanities* reflects our attempt to return storytelling to the heart of medicine. It is in these profound moments of literary and artistic expression that we find our humanity, and our strength.

The *Brown Journal of Medical Humanities* is published with the generous support of the Cogut Institute for the Humanities. We are incredibly grateful for their partnership, which has been essential to the success of our journal. We would also like to thank the individuals at Brown University and the Rhode Island School of Design who serve on our Advisory Board, providing critical feedback on the editorial process and sage insight across their many areas of expertise. We are so appreciative of the individuals and institutions who have advised us in an informal capacity throughout all stages of our founding process, including early and founding members of the *Brown Journal of World Affairs* Daniel Cruise, Alexander Scribner, Michael Soussan, and Peter Scoblic; founding members of the *Brown Political Review* Alexandros Diplas, Oliver Hudson, and Benjamin Wofford; former Head Deputy Editor of *The Medical Humanities Journal at Boston College* Katherine Montas; and Associate Director of The Pegasus Physician Writers Group at Stanford and Editor-in-Chief of *The Pegasus Review* Dr. Jennifer Pien. Finally, we would like to thank our incredible authors, artists, and creators, whose work we are honored to be featuring. Our contributors range from undergraduates to medical professionals and are affiliated with various institutions. It is a privilege for us to share their stories.

With gratitude,

**Daniel Betensky, Nathalie Felton, Elyse Forman,  
Jason Peres da Silva, and Jane Zafran**  
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# FROM DIMITRI, TO ME

by Tara Ahmadi

It was a cool morning in July. With my coffee mug in one hand and about ten different pens in the other, I ran upstairs, skipping every other step. It's fascinating how many pens one loses and simultaneously finds during a hospital shift. As one of the medical students on the "yellow" team, I was the first to arrive at the workroom. I printed my patient list, took a look at the vitals and overnight events for the patients I was following, and went over my plans so that I wouldn't look lost during rounds. As I finished pre-rounding, I received a text message from the intern on my team telling me where the morning report was.

I had promised myself not to use the elevator while on internal medicine rotation. My days were long, and I couldn't go to the gym during the week. So, I took the stairs to the sixth floor and ran to the conference room. When I got there, I was barely able to catch my breath before the senior resident approached me and said, "You should take this case – it's a great one for learning about cirrhosis." I smiled back and replied, "I'd be happy to."

The night team intern began the presentation: "Forty-nine-year-old male with a history of hypertension and alcohol use disorder, found unconscious in his hotel room. In the ED, he appeared encephalopathic and had jaundice. He was given supportive care including IV fluids

and vitamins, as well as rifaximin and lactulose. Labs were ordered. He's more stable now and has been admitted to the medicine floor. Patient is originally from Russia and has been living in the US for the past fifteen years. He's a computer scientist who lost his job during the pandemic. He has an estranged son who lives in the area. He's been drinking more since he lost his job and started living in a hotel when he lost his house."

This was how I was introduced to Dimitri. I was drawn to his story. During the pandemic, many people lost their jobs. This man had lost his job and his house, and he didn't have any relationship whatsoever with his only living family member. Maybe it was the immigrant in me that was as interested in his personal life as his cirrhosis. As I sat there lost in thought, the intern on my team came over and asked me to read the patient's chart and give a five-minute presentation on the consequences of decompensated hepatic encephalopathy.

I went to see Dimitri on the medicine floor: Room 423, Bed A. I introduced myself as the medical student on the team who would be taking care of him. He opened his eyes and smiled at me. I had never seen jaundice that severe. The skin all over his body as well as his sclera were yellow. I asked him whether he knew where he was, what year it was, and the name of the president. Even though these may sound like silly questions, healthcare providers use them as a way to assess a patient's orientation to



place, time, and person. He answered where he was correctly, but as for the year, he confidently replied, "1971!" I asked once more whether he knew what year it was, and he repeated that it was 1971. I asked about the month, and he said it was October. I was confused. I glanced over my papers and saw that October of 1971 was when he was born. Thinking that he hadn't understood my question, I told him that he had given his month and year of birth. I again asked if he could tell me the year. He said, "Of course – it's 2020!" He still refused to tell me the name of the president, though. I asked him if he could tell me his son's name, since I knew the answer from his chart. He answered correctly. I completed the rest of the exam, which turned out not to be comprehensive for hepatic encephalopathy. When I returned a little while later with all the team members, Dimitri seemed alert and clear-headed. The attending physician taught me how to check for fluid waves when there is ascites and how to check for asterixis (flapping hand tremor), which is often seen in cases of cirrhosis. He reminded me to also check for palmar erythema and spider angioma. This all happened the same day I met Dimitri, and, in the end, he taught me so much about cirrhosis. He kindly let me repeat all the exams. He even joked that he would charge me each time I had to do a physical exam on him.

I learned from the senior resident on my team to use the mnemonic *VIBES* when thinking about cirrhosis:

**V** for Volume. Dimitri had ascites.

**I** for Infection or Spontaneous Bacterial Peritonitis. Dimitri's ascites fluid came back with no sign of infection, but he was given antibiotics because he was running a fever.

**B** for Variceal Bleeding. Dimitri wasn't actively bleeding when he was admitted.

**E** for Hepatic Encephalopathy. Dimitri's mental state was inconsistent throughout his stay, even during a single day. Sometimes he was confused, sometimes he was alert, and occasionally he was disoriented. At times, he was both alert and lucid. He was given lactulose, which increases colonic bacterial intake of ammonia and therefore acidifies the colon. Because the human body doesn't have the enzymes that break down lactulose, it has an

osmotic effect and increases bowel movements. When Dimitri had bowel movements, his mental state would improve, showing that the lactulose had worked and that his blood ammonia level had improved.

**S** for Screening. Dimitri was given Hep A and Hep B vaccines. His blood test didn't show any sign of Hep C infection.

I followed Dimitri for fourteen days. I went to the Gastroenterology suite with him when the doctor did an upper GI endoscopy to see if there were any esophageal varices. His esophageal veins were enlarged, and the physician banded them during his procedure.

I checked his vitals and looked at his labs every morning. I talked with his nurses to see if and how often he was having bowel movements. As a medical student, I was following only two or three patients each day, so I always had time to sit down and talk with Dimitri. He told me about his upbringing in Russia. He talked about his mother, who had been a seamstress, and who had passed away a decade ago. He also talked about his son, Sasha, who was married and had a two-year-old son. They were estranged because Dimitri and his ex-wife had had problems. His ex-wife had passed away a few years ago, but Sasha and Dimitri hadn't reconciled. Dimitri told me that his work had been his life. But when the pandemic hit, the company he'd worked for couldn't afford to keep everyone and had laid him off. He hadn't known what to do. He said that, in desperation, he had turned to drinking and watching TV. Unable to pay the mortgage on his one-bedroom apartment, he had lost it. He didn't have any family in Russia, and he didn't know anyone in the US. He said he loved Tolstoy, and asked me whether I'd read *War and Peace*. I told him that I read it in high school, and he was impressed. He said that his favorite story by Tolstoy was *The Death of Ivan Ilyich*. I told him that I had watched the play but hadn't read the novella. I promised him that I would.

One afternoon I went to check on Dimitri and found him napping. As I was about to leave the room, I thought that maybe I should wake him up to make sure he was ok. When I approached him, he opened his eyes and smiled. I asked him how he was, and he just nodded. When I asked him where he was, he said, "Moscow!" I asked the

date and he just looked at me, confused. I asked him who the president was, and he said, "Sasha!" I took out my phone to see whether Putin's nickname was Sasha. I couldn't find anything. Still Dimitri looked confused. I ran back to let the residents know, and together we returned to his room. It turned out that his encephalopathy had worsened. They gave him supportive care, and he was put back on lactulose and rifaximin. The next day he was feeling better, but he couldn't remember the events of the previous day. I continued following Dimitri for another week. He needed a new liver, but liver transplants for alcohol-associated liver disease require at least six months of abstinence.

Halfway through my rotation, the students switched teams. So, after spending two weeks following Dimitri, I wouldn't be the one caring for him anymore. I still went to see him every day at lunchtime, just to check in on him. On the second day, he told me that he was being discharged. I asked him whether he was going to a rehab center, since he didn't have any other place to go. He smiled and told me that the team had talked to his son and that he was actually going to stay with Sasha. In that moment his blue eyes were so happy, like two shining stars. I sat down and told him how overjoyed I was for him. I said I was grateful to have been part of his care team and expressed how much I had learned from him. I was thankful to the attending physician and residents who had taught me, but also to him for his patience and for letting me examine him every day. I told him that I would never forget him. He smiled at me and said, "Thank you for taking care of me! Thank you for listening to my stories! Promise me that you'll read *The Death of Ivan Ilyich*." I promised.

A few days later, I was working on a progress note when the attending from my previous team came looking for me. He wanted to know if he could talk with me for a few minutes. I followed him to a quiet space. He asked me whether I knew what had happened to Dimitri. I proudly replied, "Yes! I said goodbye to him before he left for his son's house." The attending told me that, the same day, Dimitri had had a seizure, during which he'd displaced a shoulder. He'd been transferred to a neighboring hospital where they'd found a fungal infection in his brain, and he had unfortunately passed away. The whole world suddenly stopped. I couldn't believe it.

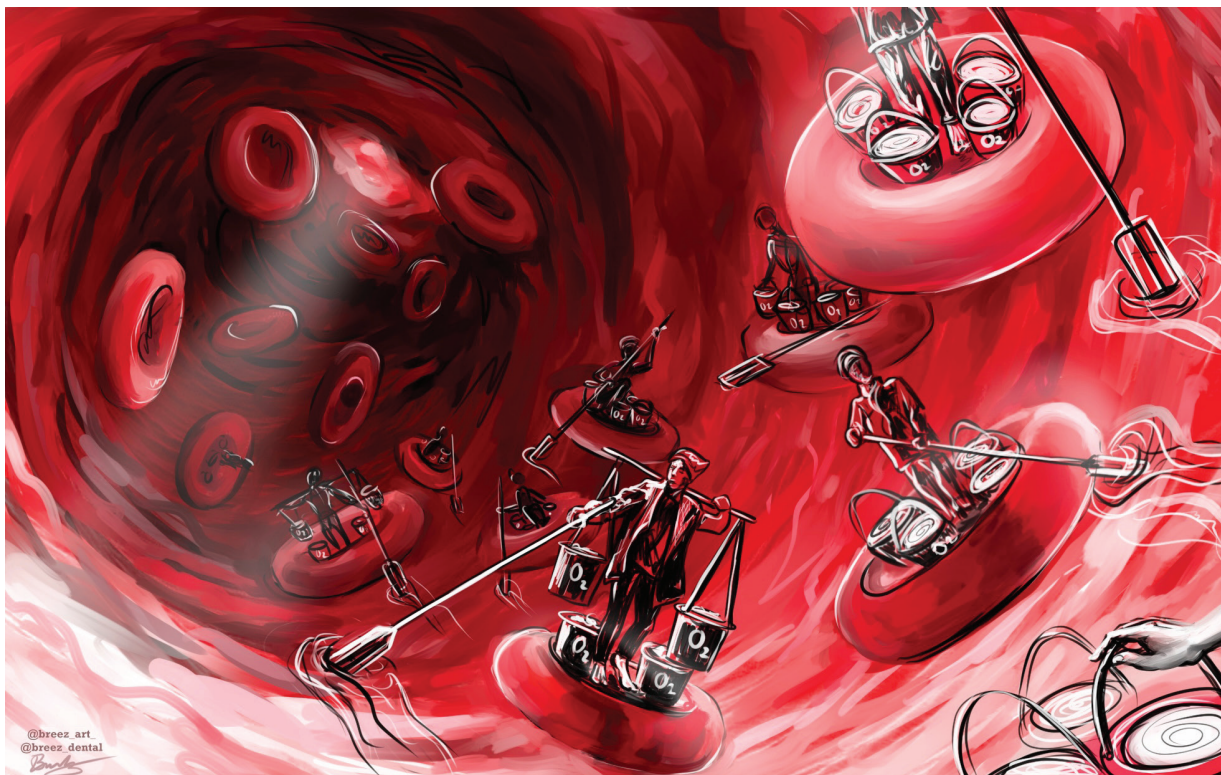
Repeatedly I said, "No! No!" In truth, I am not someone who has ever learned to mourn or to process death. As a child, I lost a second cousin and a best friend. I was told to be strong for my younger siblings. When I lost my grandmother, who had raised me and my siblings, at the age of twenty, I didn't shed a single tear, because I thought that this was how I would prove my strength. And now, affected by my past, I didn't know how to act when faced with the loss of Dimitri.

The attending physician sat down with me and told me that we'd done everything we could have for him. We had offered him the best care. No one, here or in the neighboring hospital, could have known that Dimitri had had a brain infection. Together, we went over everything we had done for him. It was difficult reliving the moments I'd spent with someone I cared for and who was now gone. Before losing Dimitri, I dealt with loss through denial – I would pretend that the loss hadn't happened. But now, remembering him, I realized that the time we'd spent together and the trust we had built had been as special to Dimitri as it was to me. We'd impacted each other's lives in a positive way, and, realizing this, I felt the heaviness in my heart begin to lift. In that moment, I finally found peace. I knew then that I would at last be able to accept death as it came. To this day I am so grateful to this attending, Dr. B., for taking the time to find me and inform me of Dimitri's passing, and for providing me with a safe space to mourn and process this loss, and ultimately, to heal.

I am also grateful to Dimitri. He was and still is a great teacher to me. We learn so much from our patients in medicine. I am glad that I had the opportunity to talk with him and thank him before he left us. I wish I could tell him that I finally learned to process and reflect on death, all because of him. Dimitri's life and death affected both me and my medical training. I am no longer the person who denies loss. I know that I can mourn and still be strong. I know that I can carry people and their memories in my thoughts and in my heart, even after they die. I know that I can reflect on their life and cherish the moments I spent with them. I finally read *The Death of Ivan Ilyich* the following summer, and I still have a copy of it on my bookshelf. On the first page, I wrote, "To me, from Dimitri."

# BUCKETS OF OXYGEN, BUCKETS OF LOVE

by Bree Zhang



“Buckets of Oxygen, Buckets of Love” is my newest hematology-themed art. Red blood cells are like little “boats,” and hemoglobin workers stand on top of these boats, carrying 4 iron buckets filled with oxygen to supply our body’s tissues.

I want to humanize these red blood cells as “**parents**” of our body who work hard to provide us energy and life to flourish, often breaking their backs under heavy burdens to give their children’s “body” the best chance at life. **That’s why we must remember to take care of ourselves.** If our body is low on iron, we don’t have the “buckets” to carry oxygen (anemia). If we lack vitamin B12 or B9, our red blood cell “boats” will become underdeveloped, swelling abnormally large and causing our “boat factory” (bone marrow) to produce fewer blood cells.

Importantly, I want to acknowledge: **just as not everyone is born with healthy red blood cells, not everyone is born with the best partners or complete set of parents, leaving many people deficient in the “oxygen” of life: love, care, support.** While I was recently reminded of the importance of nourishment by my parents, I know that not everyone has the same opportunity to access the proper nourishment—let alone receive a reminder. In the US, nearly half (45%) of pregnancies are unintended, which can result in adverse health outcomes (low birthweight, postpartum depression, parental stress, abuse, neglect, maternal mortality).

So, this artwork is a reflection. I’m reminded of what I’m grateful for, and I’m also reminded that **healthcare access and reproductive rights** are essential for us to receive buckets of oxygen and buckets of love.



# THE LIFESPAN OF RHODE ISLAND HOSPITAL

by John Lin

This huddle of six neurosurgeons and students must have been a familiar sight in this long hallway. Their colleagues—all decked out in scrubs—brushed past us, occasionally nodding and waving.

I listened carefully as Dr. Curtis Doberstein and his team reviewed their patient’s file. Mr. R had suffered from a stroke ten days ago, and he had been referred to the Rhode Island Hospital Comprehensive Stroke Center—the only one in the state. As the lead neurosurgeon on the case, Dr. Doberstein would be in charge of Mr. R’s carotid stenting to prevent further strokes.

“He’s been through a lot,” Dr. Doberstein said solemnly. Everyone murmured in agreement. I nodded too, thinking about my now-deceased grandfather. After his first stroke, my grandfather was hospitalized but recovered slowly and unsteadily. After his second stroke, he was paralyzed for the rest of his life. He never had access to this life-saving procedure.

“Let’s do this,” Dr. Doberstein declared, leading the way into the operating room. Everyone jumped into action with his entrance—the anesthesiologist, nurses, and technicians.

Armed only with a notepad and a pen, I stood and sketched as the residents began slicing into Mr. R. I watched as they carefully guided a catheter to his neck using the live angiogram showing his arteries on screen. They dislodged the plaque, widened his carotid artery, and inserted a stent to keep the artery from narrowing again. When we debriefed and departed two hours later, Mr. R left with a significantly lower risk of another stroke (Brott 2016).

Dr. Doberstein is one of the modern faces of Rhode Island Hospital. He’s the director for cerebrovascular surgery at Rhode Island Hospital and professor, vice chair, and residency program director for neurosurgery at Brown University. Every day, Dr. Doberstein researches ways to make carotid endarterectomy more efficient, teaches medical students and residents, and serves sick and poor patients in the clinic and operating room.



Stepping off the RIPTA bus into the dark, cold morning, I was struck by how Rhode Island Hospital looked much like any other. I served at the 1991-built Michael E. DeBakey Veteran Affairs Medical Center in Houston for three years, and this historic hospital seemed surprisingly similar.

Looking at the bland, beige main building of Rhode Island Hospital, it's hard to see its 160 years of history. Constructed in 1995, the Julia & Vincent Zecchino Pavilion has the appearance of a modern hospital. The Southwest Pavilion—one of the last remnants of the original campus—was demolished six years ago over the protests of the Providence Preservation Society (ArtInRuins 2022). It came down to the finances: a 2009 feasibility study determined that restoration of this 115 years-old building would take \$26.5 million but demolition would only cost \$2 million (ArtInRuins 2022).

Rhode Island Hospital was founded in 1863 as a “charitable institution,” chartered by the General Assembly “for the sick and for those who may be disabled by accidents and injuries” (Act To Incorporate The Rhode Island Hospital 1863). Their first patient, admitted on October 10, 1868, was John Sutherland (Jones 2013). A 59-year-old Providence shoemaker, he had developed a deep abscess in his jawbone after a previous tooth extraction (Act To Incorporate The Rhode Island Hospital 1863, Jones 2013). His surgery was successful, and Sutherland was discharged two months later (Aronson 2002). All patients were provided with free care, both for outpatient appointments and when they were hospitalized (Jones 2013, Rhode Island Hospital 1923). To this day, Rhode Island Hospital provides \$160 million in charity and community care as Rhode Island’s largest safety-net hospital (Lifespan 2022).

With the opening of Rhode Island Hospital in 1868, Professor William Gammell of Brown University declared his hope that “the hospital could be in itself a school of practical medicine of the greatest importance to the profession” (Wing 1994, Garland 1963). Education became a central mission of the Rhode Island Hospital from its beginning (Garland 1963). Two medical school graduates would be appointed by the Board of Trustees to complete a six-month medical or surgical internship, which grew to three interns by 1884 and four by 1890 (Wing 1994). A formal

two-year internship was established in 1890, providing six interns with rotating experiences in medicine, surgery, and the subspecialties (Wing 1994). In 1902, there were eleven interns, and the Rhode Island Hospital established an association of alumni with four-year reunions (Wing 1994).

Near the turn of the century, the hospital declared that its “chief function was the charitable care of the sick as well as good training of doctors and nurses,” and internships likewise expanded to 17 physicians in 1904, 18 in 1908, and 20 in 1909 (Wing 1994). Interns began attending ambulance rides as an early emergency medical service in 1911, and intern Dr. Henry Clough developed bromide photographic paper for electrocardiograms that would become a national standard (Wing 1994). Formal post-internship residency programs were established in medicine in 1925 and pathology in 1929, and specialized education grew rapidly after affiliation with Brown’s medical school in 1959 (Wing 1994). Now, Rhode Island Hospital trains hundreds of residents in 90 residency programs across specialties (Lifespan 2022).

Nurses were critical for patient care from the beginning, but it wasn’t until 1879 that Rhode Island Hospital hired its first nurse with formal training (Jones 2013). Three years later, Sarah Gray became nursing chief and established the Rhode Island Hospital Training School for Nurses (Rhode Island Hospital Nurses Alumnae Association 1931). Beginning with three students, the school grew to become the fifth largest in the country—only dwarfed by the likes of Johns Hopkins and Bellevue Hospital in New York (Rhode Island Hospital Nurses Alumnae Association 1931, Wing 1994). To provide a comprehensive undergraduate education, the hospital also recruited University of Rhode Island instructors to come to campus and teach non-nursing subjects (Powers 2012). Despite living in a small building on a hospital campus, several alumni reported enjoying their years at the nursing school, traversing the campus through dark underground tunnels and walking to downtown Providence with friends (Powers 2012, Tew 2016).

In 1931, the Rhode Island Hospital Training School for Nurses and Pembroke College of Brown University began jointly offering a nursing program (Mitchell 1993). This five-year program “was started primarily to prepare... young women

for the position of instructors in nursing schools," according to Helen Potter, Superintendent of the Training School (Rhode Island Hospital Nurses Alumnae Association 1931). Students also trained in infectious diseases at the now-defunct Charles V. Chapin Hospital, obstetrics at Providence Lying-In Hospital, psychiatry at Butler Hospital, and public health at the Providence District Nursing Association (Mitchell 1993). Brown University President Wriston was reluctant to appoint nursing school instructors (viewed as subcollegiate) to Brown's faculty, and the hospital school was concerned about Brown's influence of the hospital (Mitchell 1993).

After the National Nursing Accrediting Service visited in 1950 and accredited the hospital nursing school but not the joint five-year program, Brown University discontinued its nursing program for the class of 1965 (Dalton 2020). A decade afterward, as enrollment in the hospital's three-year school dropped, the hospital closed its nursing school in 1973 (Jones 2013). That year, half of all nurses working in Rhode Island had attended the Rhode Island Hospital School of Nursing (Jones 2013). Their dormitories, Aldrich and Gerry Houses, have since been repurposed for graduate medical education; my brother lived in Gerry House just two months ago.

In 1960, Brown University President Barnaby Keeney commissioned a study group to review the re-establishment of Brown's medical school, which had closed in 1827 after President Francis Wayland required that all faculty reside on campus to help supervise the student body (Wing 1994). Physicians and writers have blamed the closure of Brown's first medical school for Rhode Island's long delay in establishing a general hospital (Jones 2013, Aronson 2002). In turn, the re-establishment of Brown's medical school proved to be a major boon for Rhode Island Hospital, "transform[ing] Rhode Island Hospital from a strong community hospital into an academic medical center" (Jones 2013).

More than a century after Rhode Island Hospital was founded, Brown University officially graduated the first class of medical students in Rhode Island since the 1820s in 1975 (Dalton 2020). Rhode Island Hospital became the largest of eight teaching hospitals for Brown, "attract[ing] nationally ranked physicians and thus providing a higher level of medical care"

(Jones 2013). With new prominence, the hospital campus continued expanding, adding a north wing to the Jane Brown Building for Private Patients, constructing the Meehan hematology building, and building the Ambulatory Patient Center (Jones 2013). In 1980, Rhode Island Hospital was designated the state's trauma center and opened the Davol Building for Emergency and Surgical Services (Jones 2013).

This Brown-fueled growth has even been quantified. As healthcare costs rose in the state and across the country, the Rhode Island Department of Health began investigating the factors contributing to hospital capital spending (Linnane 1988). Capital expenditures for Rhode Island Hospital skyrocketed from under \$2 million in 1979 to \$12.5 million in 1986, from \$7 million to \$30 million for other Brown affiliates, but from \$5 million to \$9.8 million for non-affiliated hospitals in the same period (Linnane 1988).

When Dr. George Waterman spoke at the hospital's annual meeting in 1947, he called for the hospital to take care of patients, provide strong physician training, and conduct innovative research (Jones 2013). Rhode Island Hospital began research laboratories for pathology in 1945, as well as open-heart surgery and cancer therapy in 1954 (Jones 2013). Affiliating with Brown accelerated the expansion of research at Rhode Island Hospital, which recruited renowned researchers such as physician-in-chief Dr. Milton Hamolsky and surgeon-in-chief Dr. Donald Gann. This year, Rhode Island Hospital and its affiliates were awarded \$92 million in research funding and conducted approximately 1,500 clinical trials (Lifespan 2022). With the enactment of an aligned research collaboration agreement between Rhode Island Hospital, Brown University, and Care New England last month, the future is bright for research in Rhode Island (Cambra 2022).

Founded amidst the American Civil War, Rhode Island Hospital is no stranger to crisis. When the United States entered World War I on April 6, 1917, the hospital supplied most of the staff for Navy Base Hospital Number Four in Ireland (Jones 2013). After a massive explosion in Nova Scotia that killed 2,000 and injured 6,000 in December 1917, Rhode Island Hospital staff traveled to Halifax to help (Jones 2013). In 1918, the influenza

pandemic brought 1,373 patients to the hospital and sickened half of the hospital's nurses; nursing students stepped up to help (Jones 2013). During the Great Depression, the hospital slashed wages by 10% and began charging 10 cents and then 25 cents for previously-free outpatient care (Jones 2013). Nearly half of the hospital's medical staff and 254 nursing students served in the military during World War II, organizing the 48th Evacuation Hospital in India, Burma, and China (Jones 2013). In 2003, The Station nightclub fire killed 100 people and injured more than 200 (Jones 2013). In the past three years, Rhode Island Hospital's healthcare workers have served on the frontlines of the COVID-19 pandemic, even amidst nationwide mask shortages and seemingly endless virus surges. Dr. Megan Ranney, a Brown- and Rhode Island Hospital-affiliated emergency physician, founded and organized GetUsPPE to help distribute personal protective equipment for healthcare workers nationwide (Gondi 2020).

As a safety-net hospital dedicated to caring for low-income patients, Rhode Island Hospital has sometimes suffered from budget deficits, such as during the Great Depression and the World Wars (Jones 2013, Rhode Island Hospital 1923). Starting in 1986, Rhode Island Hospital faced large deficits; accordingly, they laid off employees and sought new sources of revenue such as parking fees but ultimately achieved a \$2 million surplus by 1991 (Jones 2013). New cost-cutting measures, such as a self-insurance plan with a high monthly premium, sparked three successful unionization drives in 1993 (Jones 2013). Secret negotiations between the board chairmen at the Rhode Island Hospital and Miriam Hospital led to their merger in 1993 as the Lifespan Corporation (Jones 2013). Since then, five more affiliates have joined Lifespan, and a competing network of five hospitals called Care New England formed in 1996 (Greenhouse 2021).

However, consolidation has not entirely fixed Rhode Island Hospital's financial woes. In 2019, Lifespan suffered a net loss of \$35 million, which worsened in 2020 and 2021 (and was only offset by federal stimulus funding) (Nesi 2019, Nesi 2020). Lifespan and Care New England have proposed merging three times but have failed to receive government approval (Anderson 2022, Nadirashvili 2022). Now, Rhode Island Hospital must chart a new path to financial sustainability.

At times, a charitable clinic. At times, a college. At times, a research institution. Throughout its history, Rhode Island Hospital has been many things to many people. Today, nearly none of its original campus remains (Pratt 1956, Dewolf 1957). The story of Rhode Island Hospital is so relevant because it mirrors the history of Rhode Island itself—its ups and downs, its failures and successes, its losses and gains. This historic institution, once struggling to adapt to modernity, is now well-positioned to take on the 21st century. A century ago, facing a deficit equivalent to \$5 million today, the hospital declared, "This worthy institution often fails to receive the recognition merited, because of the quiet and unostentatious manner in which it goes about its business" (Gondi 2020). Through patient care, education, and research, Rhode Island Hospital has served Rhode Islanders for more than a century and its future is tied to the fate of our state.

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# GREEN GIANT

by Simone Nemes



# BIRTHDAY TWIN

by Trisha Mukerjee

By the time the Stage 4 cancer had crawled up, from ovaries to stomach,  
the only certainty was that she was going to suffer  
then die. A premonition

took hold of her: the reappearance of her dead father  
in her dreams, from the day he died to the day she was diagnosed.

That's the luck of a Gemini, she said, nobody believin,' instead  
cast as a hedonistic fool, as

puked up clear-green sputum, all two-faced like her youth, her health  
which hurdled unfettered –  
like an undetected meteorite.

She was 39. I was 22. Young enough  
to be unsplintered. To want so much from life.

"I want to go surrounded by people, even if it's in a hospital. I believe,  
God sent you into this room for a reason. I know you're a good person,  
you don't have to convince me. Don't hold back, birthday twin.  
Laugh, dance, cook, play. Promise me".

And standing there  
I realized I wasn't much of anything anymore.  
Fear creeping up, Lord Ombra, milky & mysterious

# SOLACE

by Trisha Mukerjee

Marcie! Marcie! Mamma! Martha! Maria! Maaah-re-ya. Marcie!

Here's a man, all he wanted was comfort. To be free & reckless, rolling back &  
forth, furtively within the confines of the hospital blanket. Wholly agitated. Ativan  
temporarily alleviated but never fully calmed. His eyes were closed but sleep  
never came. So old. Sweetest man  
ever, her daughter said. All before the fall. Then became so altered.  
The daughter, anguished &  
disarrayed, stayed as long as she could. When she left, he couldn't tell the  
difference. All night  
long, the man trembled with his Parkinson's, calling out for his daughter.

Marcie! Marcie! Mamma! Martha! Maria! Maaah-re-ya. Marcie!

# A MORE BEARABLE HOSPITAL VISIT

by Icy Liang





# READ THE ROOM

by **Eve Makoff**

I knocked lightly before I pushed the hospital room door open. Mr. Thomas was propped up in bed by several pillows. A pale yellow hand was wrapped around his wife's healthy freckled one as they spoke quietly. Hearing me, they looked up - four weary eyes latching on to my two lightly made up ones. They seemed annoyed to find me standing there. I knew incessant interruptions of sleep, of meals, and of stolen private moments like this one, were the norm in the hospital. I was the unwanted introducer of the moment.

"Who are you again?" Mrs. Thomas asked.

"Oh, we haven't met yet. Don't worry. You see so many people all day."

"You can say that again. But really, who *are* you?"

It seemed she wanted to get whatever news or activity I brought done with so she could return to her husband.

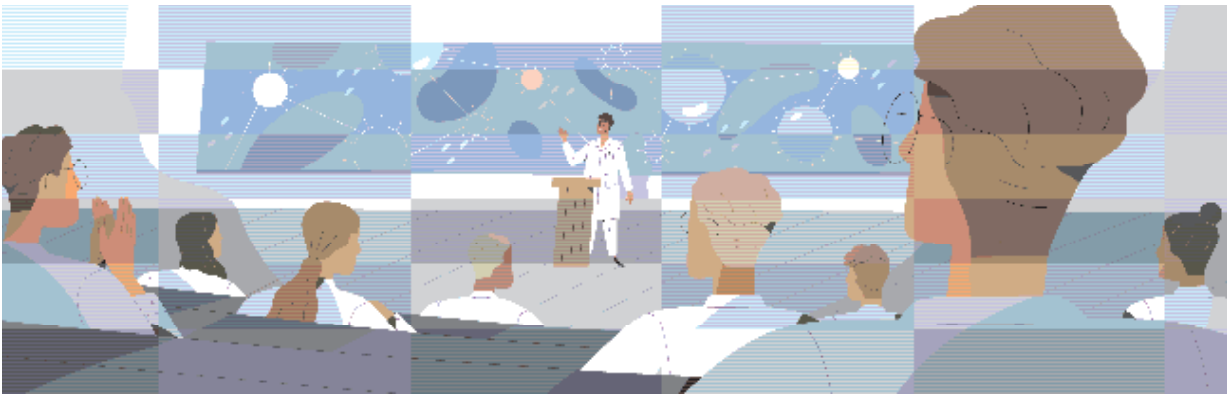
"Your team asked me to check in on you both, to see how you're doing. I'm a palliative care doctor."

The tightening of her mouth told me I'd provided just about the worst possible answer to her question.

Before entering the room, I'd read in the electronic health record that Mr. Thomas had unresectable pancreatic adenocarcinoma, one of the worst kinds of cancer there is. I saw my first patient with the disease during my surgery rotation in the 1993 when I was in my third year of medical school. The patient, a man about Mr. Thomas' age, had sunken cheeks and skin a similar pale shade of yellow. When his situation was explained as he sat in a small chair in the surgeon's office he just bowed his head and said nothing. There hadn't been any treatment options available to him at the time. He died three months later. Even if the average prognosis now in 2013 had extended by a year or two, I knew this disease was devastating. Even if Mr. Thomas had options, my heart broke when I read his diagnosis.

At the threshold of Mr. Thomas's room, tears threatened to emerge. My chest grew heavy. In my mind I summoned questions for Mr. Thomas and his wife. *What was their understanding of what was occurring? Were plans for retirement, for travel, interrupted by his diagnosis?* (I'd heard this so many times before: "I finally got out of the rat race and then I got cancer. It's so unfair"). *Did they have children or grandchildren who needed their care? Was there a job to wrap up? How were they coping with the life shattering diagnosis?* And, most importantly, *What were his goals for his life and his death?* Once I felt comfortable emerging from my





awkward place, neither inside nor outside of Mr. Thomas's room, I hoped to create the space for these conversations to occur. But somehow I felt reluctant to step in. And I soon found out why.

"Could you please leave now?"

Mrs. Thomas' sharp tone jolted me back to the scene.

"I'm sorry? I just got here..."

"But you're already not helping. You're not helping at all."

I still didn't move.

She went on: "You see. You have death in your eyes. Nobody needs to see that right now. I'd appreciate it if you would go and never come back."

Mr. Thomas looked away, his silence signaling concurrence with his wife's request. Stunned, I turned to leave. I walked quickly down the hallway, the shiny gray concrete and the clack of my heels comforting in their familiarity as I tried to digest this interaction.

I was horrified. Humiliated. Ashamed. This had never happened to me before. Before that moment, I'd prided myself on my ability to connect with people in all kinds of ways. I felt like I'd failed at my most important task: to provide comfort. In fact, I'd done exactly the opposite, I'd caused discomfort, even anger. But also, I was confused. What had I done wrong? Did I annoy them somehow? Was I too emotional? Did the visible spark of my own pain ignite theirs? Was the death she saw in my eyes

an indication that I revealed something that I should have kept hidden?

What had just happened?

\*

Doctors feel.

One way or another we absorb, and metabolize, the losses that face us everyday at work, especially in fields like palliative care, emergency medicine, and the intensive care unit. And sometimes we can't hide our feelings. Many of us were taught in the course of our education to steel ourselves so we can better weather the devastations we confront. We were also taught to deny our feelings, if they do emerge, in order to earn the confidence of our patients and colleagues. But after years of buying into these mindsets, instilled by the so-called "hidden curriculum" — the unwritten code conveyed in medical education that says we should keep our distance and become inured to the impact of life and death crises — I came to believe they were not only a prescription for suboptimal medical care, they were dangerous to everyone involved. And research backs this up.

What's become clear is patients prefer doctors who show emotions (Mercer 2016). And beyond patient (and family) preference, it's been shown that clinicians who deny, or who aren't aware of, their feelings risk harming their patients, and themselves. One review, utilizing self-report by physicians lays out the extent of the potential damages:

Unrecognized emotions may impede the use of patient-centered skills and may

be associated with harmful behaviors, such as inappropriately interrupting the patient, changing the subject, avoiding patients' psychological issues, avoiding bonding with patients to prevent suffering, avoiding conducting certain medical procedures again, or avoiding patients altogether. One study showed that physicians themselves perceive their emotional states as influencing medical acts such as prescribing, talking to patients, and referring. In addition, lack of recognition of one's emotions and low-level choices, more than clinical knowledge or medical skills, have been proposed to be associated with medical error. Along with the effects of emotional unawareness on patient care, research has also examined the impact of physicians' emotions on their own well-being. Unexplored feelings may be associated with distress, poor judgment, loss of privileges, social isolation, increased workload, risk of litigation, burnout, reduced work satisfaction, and an increase in alcohol and other substance use (Vilela da Silva 2016)".

In other words, it's not only okay for physicians to acknowledge their emotions, it's critical for the quality care of patients and for personal well-being. Grief can be too much to bear with a clear head — even for a doctor. It's about doctors paying attention to where they are, psychologically and emotionally, and deciding if they are ready to show up with the focus and integrity their work demands. It's also about doctors allowing themselves to know their limits, and giving themselves permission to step away and take care of themselves if the emotional burden becomes too great. The need for these kinds of skills has started to be acknowledged in healthcare, especially in light of the stresses of the COVID pandemic. This focus has contributed to the further integration of the arts and humanities into the education of healthcare workers. Activities like narrative medicine enhance the skill of self-reflection, helping clinicians identify and manage feelings that arise in the practice of medicine (Charon 2001). Detaching ourselves from the experience of transformative moments, like a terminal diagnosis or a life passing on to death, leaves our patients and their families alone right when they need us the most. It can also contribute to a physician's own feelings of isolation and helplessness. If, instead, we allow ourselves to be vulnerable, to identify and acknowledge

whatever arises for us, and to authentically connect to our patients, and ourselves as a result, we create the greatest opportunity for healing to occur.

What happened with Mr. and Mrs. Thomas did not change my fundamental belief that emotions are not liabilities, but rather portals into the deepest kind of service to self and others. But it did push me to add narrative humility to my approach to patients and families. Although I didn't know the term then, narrative humility — as coined by physician, author, and narrative medicine scholar Sayantani DasGupta — reminds us that every human being comes with a unique makeup and set of experiences which create who they are, and how they show up in life. As practitioners, in addition to developing emotional awareness and self-acceptance, we need to learn to read the rooms we enter with curiosity and the knowledge that we are entering someone else's space whose contexts and rules we may not know. In doing so, we let the patient set the stage, and perhaps the rhythm and tone, for how our interactions unfold.

I now recognize what I missed, and what might have changed the outcome of my interaction with this family. When I arrived it was clear I was interrupting a sacred moment. Not only because with life-limiting illness every interaction is precious, but because I witnessed it from the doorway: the heads bowed together, the somber faces, the hands pressed together. I might have paused and taken a moment to process what I was seeing. And I might have come back later when, perhaps, they'd have been more ready to open their circle.

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# JUST MARCIA

by Annika Divakar

*This podcast episode, "Just Marcia," was created as the first installment in a series about conversations with non-physician professionals in the clinical setting to examine their perspective on healing. The episode centers around end-of-life care with Marcia Brennan, a resident artist at MD Anderson Cancer Center, and explores themes that go beyond the traditional role of healthcare providers in medicine.*



# THE DISGUSTINGLY INNOCENT ILL: MEDICAL LITERATURE'S INFLUENCE ON THE ISOLATION OF ILLNESS

by Daniel Betensky

*"The worst thing about being sick in America is that you are booted out of the parade. Americans have no use for the sick. That's America. It's just no country for the infirm."*

Tony Kushner, "Angels in America"

While Tony Kushner distinguishes America as a place where illness is not accepted by society, this trend can be applied to many societies throughout history as well. Again and again those suffering from illness are "booted out of the parade" and secluded from the rest of society. "Booted from the parade" is an incredibly accurate statement. A "parade" is generally meant to celebrate some special occasion or event, and, by becoming ill and being "booted" or kicked out, you are no longer able to join in the celebration of everyday life. Not only must the "infirm" suffer through their illnesses, but they are also subjected to ostracism from their communities. An ill individual is someone who

most needs companionship. However, for some reason our society instinctively expels the sick from our lives and leaves them to suffer alone. This tendency to isolate the ill is also apparent in both current and historical medical literature. This alienation of the sick in literature reflects the societal impulse noted by Kushner, and it exposes this horrible trend to a careful reader. How would the portrayal of the sick in fictional works influence a reader's opinion of whether to isolate these individuals in reality? Much of medical literature attempts to influence its readers to feel empathy for the sick by portraying them as helpless while simultaneously perpetuating their alienation and isolation through the employment of vivid and disgusting language to describe them.

Society's isolation of those suffering from illness presents itself in a significant number of stories. Even in the times of Ancient Greece, it appears illness led to ostracization and people were instinctually driven away from it. In Sophocles' *Philoctetes*, Philoctetes tells Neoptolemus the



story of how he arrived at the island, and how “the twin commanders and the lord of Ithaca expelled [him] in shame to be this lonesome castaway” because he was “reduced by a harsh disease, struck down, consumed alive by a snake bite” (Sophocles 264–267). According to Philoctetes, his infected foot led to his exile on this uninhabited island. The Oxford English Dictionary defines “expel” as “to eject by force,” which suggests Philoctetes had no opinion in his banishment and that it defied his wishes. Rather than care for him and attempt to heal the infection, Odysseus instinctively ejected him from their army and entire society. Additionally, his illness made him a “lonesome castaway,” again implying society threw him away and rejected his presence. Not only was Philoctetes “booted out of the parade” and of the war, but his exile further disabled him by bringing him “shame,” an extra pain for his conscience on top of the physical ailment.

In “The Death of Ivan Ilych,” Tolstoy depicts Ivan as being entirely alone and secluded from his friends and family despite their constant presence around him. The narrator notes that Ivan Ilych “was left alone with the consciousness that his life was poisoned and he was poisoning the lives of others, that this poison did not weaken but penetrated more and more deeply into his whole being,” and that there was “no one who understood or pitied him” (Tolstoy 125–126). The narrator’s use of the verb, “poison,” to describe the effects of sickness reveals that Ilych believes his disease not only hurts others but *infects* their lives and makes them ill as well. Illness is once again characterized as an alienating factor, but this isolation is slightly different because Ivan’s friends and family remain around him and help take care of him. He blocks himself off from society because *he* believes his illness is a “poison” both to himself and others around him. However, unlike Philoctetes (who was abandoned alone on an island), nobody made it clear to Ilych that his illness was dragging others down, so the fact that he subconsciously understands illness should isolate him suggests he has internalized this societal tendency. Furthermore, if the “poison” is a metaphor for his disease, its “penetration into his being” implies he is defining himself by his illness. Ilych’s disease is corrupting his humanity.

While, “The Death of Ivan Ilych,” stresses the self

alienation due to illness, Kafka’s “Metamorphosis” reflects the intrinsic societal instinct to separate oneself from a sick individual by telling the story of a young boy who happened to somehow turn into a beetle. Regardless of how the reader interprets Gregor’s transformation, the physical change presents itself as some malignancy or disability that his family immediately wants to exile. While his employer “clap[s] one hand before his open mouth and slowly back[s] away as if driven by some invisible steady pressure” (Kafka 13), his father gives Gregor “a strong push which [is] literally a deliverance” into the room and “the door slam[s] behind him with the stick,” leaving only “silence” (Kafka 17). Without thinking or attempting to talk to Gregor, his repulsed father decides to lock him away in his room. Again, a physical ailment has led to the isolation of the individual suffering from it. The fact that the chief clerk was driven away “by some invisible steady pressure” suggests some people naturally are unable to empathize with the ill and instead seek separation from them. Also, the narrator characterizes this isolation as a “deliverance,” which traditionally describes the process of being set free; this is the opposite, an act of confinement for Gregor. While this word might seem to describe Gregor’s seclusion, perhaps it actually is being used to characterize the family and their newfound freedom from interacting with illness.

Finally, in Kushner’s play, “Angels in America,” Louis’ desertion of Prior after his AIDS diagnosis both reaffirms the previously noted tendency to isolate illness and suggests illness can overpower love. As Prior is lying ill in the hospital, Louis announces his plans to leave him. He claims that his departure “isn’t a crime, just an inevitable consequence” and that he has “to find some way to save himself” (Kushner 1.2.9). The word “inevitable” indicates his leaving Prior is an inescapable fact of life. Then, “consequence” suggests there is a direct cause and effect relationship between diagnosis and isolation, one naturally leads to the other. By calling his desertion an “inevitable consequence,” Louis perpetuates the historical trend to isolate the sick. Additionally, his argument that he needs “to save himself” illustrates that he is aware of his actions, but he goes through with the abandonment regardless. His concern for his own health outweighs his love for Prior, even in his time of greatest need. It is hard to imagine someone can give up on a loved one like this

and still truly love them: it seems the illness and infection were able to terrify the love out of Louis.

The isolation of the sick runs rampant through much of medical literature. What remains unanswered is how the language of the stories shape the readers opinion of the ill and their alienation from society and even loved ones. Do the texts encourage the audience to continue their current path of confinement? Or, do they evoke empathy and make the reader ashamed to be a part of a society that does this? A close analysis of the specific language used by the authors in their stories suggests the texts can both induce compassion *and* incite further isolation.

Sophocles' portrayal of Philoctetes as helpless and deserving of pity helps both to evoke the audience's empathy for him and encourage opposition to his abandonment. Throughout the play, the chorus and Neoptolemus recognize the need to have compassion for Philoctetes despite the horrid nature of his disease. The chorus tells Neoptolemus that they "pity [Philoctetes]" because he has "none of men to bring him aid, no friendly face to keep him company," and he is a "poor wretch and always all alone, sad victim of a fell disease, and in despair at every need confronting him" (Sophocles 169-175). The fact that this "pity" comes from the chorus holds greater power than if it were to come from any other character because, in Greek tragedy, it is meant to represent the voice of the public and develop a connection between the characters and the audience. The chorus's compassion for Philoctetes indicates to the audience that he should not be punished and exiled for his illness but rather taken care of and loved. Having the chorus tell Neoptolemus to pity him also suggests Sophocles' goal might be for the audience to support Philoctetes and feel his pain. Furthermore, by calling Philoctetes "a sad victim of a fell disease," the chorus removes any blame for his ailments from him: the chorus' use of "victim" and "fell" presents Philoctetes as being powerless over his situation, and the infection as a deadly villain. This characterization of Philoctetes as helpless and innocent both induces the audience to empathize with him and incites them to instead target their fury at the infection.

Much like Sophocles' characterization of Philoctetes, Tolstoy's language and imagery portrays Ivan Ilych as a passive figure dominated by his illness, despite its inhuman

and material nature. The disease is actively attacking him, and just like Philoctetes, Ilych is a helpless victim to the assault. Tolstoy writes that Ilych "and his pain were being thrust into a narrow, deep black sack, but though they were pushed further and further in they could not be pushed to the bottom" (Tolstoy 146). First, Tolstoy uses the passive voice to describe Ilych by saying he was "being thrust," which immediately indicates to the reader that Ilych is innocent and can do little to aid his situation. Then, the imagery of being stuffed "into a narrow, deep black sack" reflects that of a kidnapping or capturing, which suggests Ivan is not passively accepting illness, but that it is holding him against his will. An intrinsic fear of being kidnapped along with Ilych's portrayal as a passive victim to the cruel infection would allow the reader to connect and empathize with him. Additionally, Tolstoy depicts this "sack" as being endless when he notes "they could not be pushed to the bottom." The concept of something being never-ending can induce despair in an individual because it removes any hope of leaving the situation. Tolstoy's inclusion of the sack imagery and its endless nature allows the reader to envision Ivan's mental state and to understand the despair and hopelessness he feels as a result of the evil illness. Once the reader can imagine how it might feel to be in pain, alone and full of despair, they would empathize with not just Ivan's plight but that of other sick people and want to reach out to them rather than support their exile from society.

In "Angels in America," Prior employs an allegory to express his fear of dying after being diagnosed with AIDS and to highlight his helpless state. He tells the story of one of his ancestors who was the captain of a ship that went under in a "winter tempest" forcing seventy women and children to climb into a rowboat. The twist is that the boat was leaky, and the crew began throwing people out to keep it afloat until only nine people were left. After finishing the tale, Prior tells Louis the following:

*I think about that story a lot now. People in a boat, waiting, terrified, while implacable, unsmiling men, irresistibly strong, seize ... maybe the person next to you, maybe you, and with no warning at all, with time only for a quick intake of air you are pitched into freezing turbulent water and salt and darkness to drown (Kushner 1.1.8).*

In this allegory, the people in the boat represent the population of AIDS patients in the 80s, the “unsmiling, irresistibly strong men” symbolize the disease, and the “freezing turbulent water” embodies death. By describing the men as “irresistibly strong” (and therefore the disease as well), Prior places all of the power with the disease rather than himself. He implies that he (like the women and children) is at the mercy of his illness, which is especially true for someone diagnosed with AIDS. Also, Prior (like Tolstoy’s narrator) uses the passive voice to talk about the people in the boat, furthering their image as powerless and weak compared to the men (or illness). Then, the word “seize” alludes again to the imagery of kidnapping and capture, which implies AIDS patients are victims of violent assaults rather than villains sickening the community. Once again, the reader encounters an image of the sick having no control over their fates or their diseases. By portraying the ill in this helpless manner, Prior actively attempts to receive compassion from Louis but also induces empathy from the reader.

However, the texts also happen to contain vivid, vile language that coerces the reader to imagine being around a sick person would be unpleasant and would combat any instinct to empathize with and care for the ill. When Odysseus is describing the reason he abandoned Philoctetes on the island, he tells Neoptolemus that his “foot, consumed by disease, oozed pus” which prevented them from “peacefully making offerings of drink or sacrifice, because his wild, ill omened cries had completely paralyzed their force in its entirety, as he screamed and groaned” (Sophocles 7-10). The visual image of “oozing pus” is strong and disturbing: the picture serves to evoke a response of disgust from the audience and help explain the Greek’s reaction to his illness and his exile. Next Sophocles asks the audience to imagine experiencing “his wild, ill omened cries” and his “screaming and groaning,” none of which would be pleasant to be around. When combined with the image of the “oozing pus” in his foot, the audience can deduce that the reality of living through this experience would have been horrible for the Greeks. Also, the real life image was powerful enough to “paralyze” the Greek army, which would further terrify the assumedly less brave audience. Being exposed to the vivid images and sounds of illness would drive the audience to avoid encountering this sort of situation in

their own lives and instead to isolate the sick as Odysseus did.

Similarly, Tolstoy describes in great detail the extent of Ivan Ilych’s illness and the work taking care of him entails, which would drive many to avoid him and his illness. As Ilych nears death, his illness becomes more pronounced, shifting from a mere pain in his side to a much more gruesome plague. The narrator claims that as he lay on his deathbed “something rattled in his throat, his emaciated body twitched, then the gasping and rattle became less and less frequent” (Tolstoy 156). Tolstoy invites the reader to imagine both auditory and visual stimuli with the “rattling” and “twitching” and “emaciated” body. The verb “rattle” forces the audience to hear the short, rapid percussive sounds emanating from Ilych’s ill throat. Then, “emaciated” calls to mind Ivan’s incredibly thin, muscle-less body, and “twitched” invokes the imagery of being pulled sharply one way and another. The great detail in this image would disgust any reader slightly afraid of the human body. The narrator also notes that “for his excretions also special arrangements had to be made, and this was a torment to him every time” due to the “uncleanliness, the unseemliness, and the smell, and from knowing that another person had to take part in it” (134). By commenting on Ilych’s “excretions” Tolstoy forces the reader to imagine his “smell,” the third sense he uses to describe his sick state, making his depiction even more offensive. The narrator also includes, in his description, the fact that “another person had to take part” in his illness, which would force the audience to conceive of embodying that person and cleaning up his “excretions,” a particularly nasty task. The dread of having to be around someone this sensationally repugnant and to perform the tasks of taking care of him could compel the reader to seclude themselves from the sick in their real lives.

Finally, Kushner’s descriptions of Prior’s and Roy’s illness are vivid and powerful enough that they could urge his audience to shy away from the sick. At one of his checkups Prior details the state of his health to a nurse and tells her that his “ankles [are] sore and swollen,” his “BM’s pure liquid but not bloody anymore,” and his “glands are like walnuts” (Kushner 1.3.2). The visual image comparing “glands” to “walnuts” is particularly unappetizing because it suggests someone might ingest the disease ridden organs. Also,



much like Tolstoy's narrator, Prior's mentioning of his "BM" (bowel movement) and the fact that they are "not bloody anymore" coerces the reader to visualize bloody stool. Very few people would be truly interested in taking care of this "bloody" mess, and alienating the sick would be an easy way to avoid it. Then, when Roy is nearing death, the stage directions claim "he's shockingly altered, in terrible shape" and wearing "adult diapers" over his "bare, fish-belly white legs," another quite descriptive visual (2.4.1). However, the fact that Roy is "shockingly altered" suggests that sickness is not merely a state but a process that shapes and changes a person over time. Many people fear change, so the revelation that illness can transform an individual would further drive people to keep the ill in isolation.

Evidently, literature can induce both support and opposition to society's tendency to isolate the sick. However, it is impossible to truly know whether the characterization of the ill as helpless or the vivid images of sickness in literature has a greater impact on the reader's opinion of the ill's alienation. The remaining question is whether there is a way to use literature to prevent this alienation and better integrate the ill into society. If authors were to refrain from describing illness in the vivid nature they often use, their stories

would lose much of their artistry and power. How might authors preserve the detailed imagery they now employ, but also refrain from writing in a way that demonizes images of illness? Meanwhile, there is also a possibility that literature in fact has no effect on society's opinion of the sick because most readers do not carefully think about and analyze texts in the way done here. Would limiting fiction's vivid language in the hopes of better integrating the ill into society be worth losing what makes stories so powerful, especially considering there might not be any change whatsoever? The answer to this question is incredibly subjective and unclear, but it could be worth considering in the future.

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# PLANT TORSO

by Simone Nemes



# SNAPSHOTS

by Annika Coleman

## Introduction:

It was after five college semesters that I realized that if you wish to heal, you must first humanize.

I arrived at Brown in January of 2021 at the height of the COVID pandemic. Coming from mild northern California, I hopped off the plane in Providence donning a knee-length North Face jacket with dreams of becoming a doctor and a deep love for the Spanish language.

During lockdown, I spent my time unusually: the California Healthcare Interpreting Association (CHIA) code of ethics and standards of practice booklets were analyzed meticulously. Long hours were spent talking to myself, flipping between English and Spanish, using vignettes to learn both the consecutive and simultaneous modes of interpretation. After months of preparation (and too many recordings of my own voice on my phone), I presented for my exams and earned my national certification in medical interpretation. Freshly certified and feverishly awaiting to begin my college career, I was ecstatic to launch into my academics and use my interpreter training to serve the Providence community.

Since arriving on campus, much has occurred that was to be expected: I have embarked on grueling deep dives into thermodynamics, epoxide formation, and the central dogma of biology. Through volunteering as an interpreter at the Rhode Island Free Clinic (RIFC), I have expanded my knowledge of medical terminology and Dominican colloquialisms. However, I did not expect how interwoven my studies of biology, Hispanic literature and culture, and medical interpreting would become.

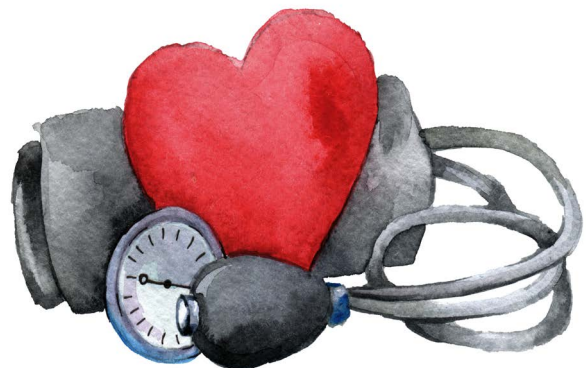
In the anthropology course “Culture and Health” and the Hispanic studies course “Health and Illness,” I was taught to question the role of the physician, the strengths and limitations of Western medicine, and how empathy in medicine—or the lack of it—can impact

diagnosis. In the Engaged Scholar course “The Latin American Diaspora in the US,” we explored the multitude of socioeconomic and political barriers that can limit the horizons and quality of life for generations of Latinx individuals. In symphony with my experiences at the clinic, these courses taught me that health cannot be separated from social context – the complex and unique narratives of each person. I felt an urgent need to document some of the stories I was hearing.

Below you will find excerpts from my “diarios,” or journal entries, which seek to synthesize the observations, questions, and conclusions I began to draw from my engagement in the classroom and at the clinic. Like a camera, I describe these experiences through snapshots: individual stories and images that take place in a short time frame. These “field notes with commentary” seek to shed light on (a) how class, race, and immigration status affect health and the quality and healthcare and (b) how, as a white woman and aspiring physician, I can work to not only develop empathy for but become an ally of marginalized communities.

I don’t pretend to be an expert in these topics. I only attempt to be human, sharing stories of other humans with the hope of sparking further discussion.

Without further ado, I present to you *Snapshots*.



## “Todo bien, gracias”

I’m in the exam room with the primary care physician and the patient. Before the appointment, the doctor reviews the intake forms with me. “Severe shoulder pain” is listed as the primary complaint. Despite knowing the answer, the doctor asks the patient what has brought him to the clinic. Surprisingly, the patient responds “Just follow up. I’m fine, thanks.” It’s only when the doctor asks him directly about his aforementioned shoulder pain that he starts to talk about the discomfort. The physical exam reveals that the pain is not minor: the patient can’t even raise his arm above shoulder height without wincing in agony.

I’ve seen this scenario repeated over and over in the clinic. The doctor asks the patient what is bothering them and the patient negates experiencing a medical problem until the physician directly raises the issue listed in their chart. This seemingly paradoxical series of events never made sense to me.

In an attempt to rationalize this pattern, I thought about something my high school friend Luis, a fellow Brown student, once told me. A Questbridge scholar, Luis comes from a working-class Mexican family in California. He explained that he never felt comfortable asking teachers for help or asking questions in class until he was a sophomore in high school. His reasoning: “When you grow up in a community with scarce resources, you learn not to ask for anything. It’s best not to ask and, that way, not take resources away from anybody else.” From Luis’ comment, we may hypothesize that, in addition to the cultural and linguistic barriers that exist between physician and patient, the socioeconomic divide is what motivates the patient to “not want to ask” for help from the doctor.

In the book *Encountering American FaultLines*, author José Itzigsohn, professor of sociology at Brown, highlights that “Providence has high rates of overall poverty...The service employment base of the city, then, yields a large proportion of working poor” (Itzigsohn 36). Specifically, in the area near Broad Street where RIFC is located, Itzigsohn comments that “In spite of the work immigrants have done to revitalize the neighborhood, it is still a poor area” (Itzigsohn 7). Thus, given that the majority of patients at RIFC form part of this “working poor,” I wonder

if we can consider socioeconomic division as the most important factor in creating distance between patient and physician.

However, the essay *Interculturalidad y Salud* by Dr. José Alejandro Almaguer González, which discusses the multicultural nature of Mexican society and proposes methods to improve relations between these various cultural groups, adds more complexity to this conclusion. This text presents the schematic of the “flower of interculturality” which visually demonstrates the plethora of factors that contribute to cultural identity.



This image serves as a reminder that numerous factors could contribute to the patient’s discomfort in the exam room: being a woman under the care of a male physician, being an immigrant, lacking a high level of education, etc. Therefore, it cannot be concluded with certainty if one factor prevails over others in producing the frequent behavior I observed in the clinic. Nonetheless, further exploring the psychology behind the “todo bien, gracias” attitude may help physicians provide a higher quality of care to this population.

## Vulnerable

I’m in the basement of Smitty-B in my class “Savage Gardens” with Professors Felipe Martínez-Pinzón and Leila Lehnen. We call our classroom “the cave” due to its unfortunate lack of windows and natural light. Co-taught in Portuguese and Spanish, without the prerequisite that all students be trilingual, the class is a kind of “linguistic experiment.” Felipe, while attempting to read a passage in his (non-native) Portuguese, comments “When we are learning, we make ourselves vulnerable.”

His mention of vulnerability comes to mind later that day in the clinic while observing the gynecologist, Dr. J, perform four Pap smears in a single shift. Even Dr. J verbally recognizes that the exam is the epitome of vulnerability. He has his script: "I know this exam is horrible, terrible, and embarrassing – but it is very important! My wife says boys should have this exam too to understand what it's like." The last joke normally gets a little chuckle out of the patient and serves to soften the bodily invasion.

Any woman would feel vulnerable during a gynecological exam. However, for minorities and immigrants, there exists another level of vulnerability due to the lack of social power they possess. In the article "Crossing Bodily, Social, and Intimate Boundaries: How Class, Ethnic, and Gender Differences Are Reproduced in Medical Training in Mexico," authors Vania Smith-Oka and Megan K. Marshalla further explore this topic through an ethnographic study of medical students in Mexico. They report that the students used the term "manitas" to describe the importance of touching the patient, or "meter mano," to train their senses (hands, ears, eyes). Intriguingly, the authors note that "In the process, one can identify how and why different patient 'types' receive different treatment and care from the physicians and medical trainees. The boundaries of their bodies are seen to be different..." They continue by highlighting that "bodies that belong to female, raced, or impoverished populations are seen to be more permeable—their boundaries are more easily breached and have fewer social rules attached to them" (Smith-Oka, Marshalla). I would add immigrants to this list of patients with fewer "bodily boundaries" and, thus, who are more vulnerable in medical settings.

In her essay *Los niños perdidos*, author Valeria Luiselli highlights that the intense vulnerability



that immigrants experience is not only present in the medical field. She comments that "Nothing should nor can be taken lightly when you ask permission to live in a country that is not yours, as you are always in a position of vulnerability" (Luiselli 18). Recognizing how the lack of social control affects immigrants daily is the first step towards truly supporting this population in challenging and vulnerable situations.

## Ashley

I had never met a child at the clinic. Since Rhode Island provides all children living in the state with medical insurance, RIFC does not offer pediatric care. After the last appointment of the day, finishing at 8:45 pm, I was helping a patient schedule her next appointment. Suddenly, little black braids nestled under the woman's arm. While the receptionist printed documents, I asked the girl her name. Shyly, she replied that her name was Ashley, she is eight years old, she likes school, and that she was very tired. Her sleepy eyes brought to mind a presentation given by Melissa Emidy, the executive director of Inspiring Minds. This organization designs programs for elementary school students in Providence to build academic and social-emotional skills. Melissa is not afraid to illuminate the troublesome reality: "We work with fantastic kids, but they are not doing well in school." Watching Ashley, yawning, waiting for her mother at 9:00 pm on a Tuesday, I began to think about the experience of children from working-class families. If their parents must work and there is no one to watch them at home, the kids must go with the parents everywhere, even if it means they'll be tired for school the next day. Can this dynamic impact the academic success of these children?

## Gringa

Another day. Another Uber ride to the clinic. As I hop in the car and hear the distinctive purring of the "rrrs" and the clarity of the short vowels, I ready myself to jump gleefully into Spanish conversation. My excitement, however, quickly fades when I realize that the driver is on the phone. The feminine voice with a strong Dominican accent coming from the speakerphone realizes that someone has entered the car and asks in Spanish, "Should

I call you back later?" Without even letting her finish her sentence, the driver laughs and responds, "No, don't worry, I'm with a *blanquita*." When we arrive at the clinic, I open the door and, with a smile, quip "*Que tengas buen día*." The driver nearly jumped out of his seat.

In the clinic, three patients ask me, "You're Spanish, right?" This comment is not new: for years, when Latinos notice that I lack the "*aceintow americanow*" but don't have a pale complexion and uncontrollable blonde curls, the only explanation they can conjure is that "she must be from Europe." I must admit I feel proud to be confused with a native Spanish speaker: the result of years of obsessively devouring episodes of *El Internado*, reading pages upon pages of Isabel Allende, Laura Esquivel, and Gabriel García Márquez, and developing creative strategies to ~ casually ~ enter into conversation with Spanish speakers in the supermarket. However, I think the pride I feel goes deeper than simple satisfaction with my linguistic capabilities: if I am Spanish, I am not a gringa.

As a white woman from northern California, I have long wondered: what is the definition of "gringo"? Is there a way to escape the label?

Various texts suggest that the gringo is the enemy of the Latino:

In her work *Borderlands/La Frontera*, Gloria Anzaldúa defines the gringo as someone "locked into the fiction of white superiority" and as the people who "seized complete political power, stripping Indians and Mexicans of their land while their feet were still rooted in it" (Anzaldúa 245). With these descriptions, Anzaldúa brings to light the association between the terms "gringo," social oppression, and conquest.

In the documentary *Latino Americans: Pride and Prejudice*, the chicano activist José Angel Gutiérrez declares that "We recognized that the barriers to our integrating into the society and to uplifting ourselves is the gringo...so, yes, the gringo must go" (*Latino Americans: Pride and Prejudice* 00:38:35). Gutiérrez's comment expresses that there exists such fervent disdain of the gringo within the Latina community that the two groups cannot exist in harmony.

Finally, in her poem, "Dear White Girls in my Spanish Class," Ariana Brown adds to the definition of the gringo, demonstrating that

it is synonymous with the propagation of discrimination and ignorance of Latin cultures. Brown critiques the "gringas" in her class declaring emphatically "I bet you thought this class would be easy, since Spanish is what poor brown people speak, right?" and "I see you – stumbling so hard you laugh through entire sentences because my ancestors are a punchline" (Brown). Here, Brown highlights (1) the lack of respect that she feels, as a Latina, from the gringos in the US and (2) the widespread preconception in the US that Latinos are a poor and uneducated people, a prejudice which simplifies – or even erases – the richness and complexity of Latina culture.

Thus, if being a "gringo" means being an oppressor, an "obstacle to progress," or simply prejudiced, I wonder if race is truly a central component of the definition of the gringo. Can an Asian or African American individual be a gringo? I don't know, and I don't think I have the power to decide.

The only thing I know: I will never be able to change the fact that I am a "*blanquita*." However, I never want to be the enemy of the Latino.

## Mirror

I'm working again with the gynecologist Dr. J. Nothing new. I prepare to interpret the same script as always (*I know that this exam is horrible, embarrassing...my wife says...*). We go into the exam room, and I go to introduce myself to the patient when suddenly. Something new. The patient seems young – very young – and I feel strange referring to her in the formal "usted." It turns out she's Colombian, and she is the same age as me. Dr. J prescribes her the same medication that I take.

I had never attended to a patient who was my age. I felt as if I was looking into a warped mirror that showed how my life could have been if I had grown up in another social context: in another country, speaking another language, without such strong familial encouragement to concentrate on my academics.

As I walk the patient to the check-out desk, the girl shows me her Instagram account, and we speak to each other using the informal "tú." And the last thing she asks me: "*You're Spanish right?*"

# THROUGH A LEARNER'S LENSES

by Madeleine Lee



A learner of medicine dons a pair of glasses with a different aspect of medicine illustrated in each lens. In the left lens, the learner sees a physician collaborating with a patient to develop a course of action best suited for the patient's needs. The physician is smiling and happy to work in tandem with the patient. However, physicians often have to make difficult decisions regarding patient care. In the right lens, the same physician is alone and rests her head on her knees, evoking feelings of stress and fatigue. I used color to underscore the physician's emotional polarities. Bright yellow conveys positive feelings while muted gray portrays negative ones.

These illustrations demonstrate conflict to highlight the wide range of emotions that can be experienced by those working in the healthcare field, especially in response to weighing various factors involved in the complex clinical decision-making process. Understanding the personal impact that clinical decision-making has on healthcare professionals not only sheds light on the way in which nonclinical factors affect medical care but also paves the way for learners of medicine to be cognizant of how their careers will shape them.

# THE MAKER'S MARK ON MY HEART

by Jocelyn Nieves

My dad's birthday and mine are one day apart. He's the 13<sup>th</sup>, and I'm the 14<sup>th</sup>. But we like to keep it simple and say that we share our birthdays. Last year's birthday was just like the one before, and the one before that. We always made a point to do something together as a family—my dad, my stepmom, and I—before I celebrated separately with my friends. The brownies were baking in the oven, filling the house with a warm, chocolatey aroma. I sat on the couch next to my stepmom, Willow, while my dad stood behind us with his arms crossed (as usual) while we watched our favorite show: *Law and Order: Special Victims Unit*.

**Beep! Beep! Beep!**

Ahh finally! The brownies were done. I jumped up with excitement to take them out of the oven, and my dad marched behind with the candles and matches. There it was: a pan of brownies with a big "6" and "0" for my dad and a "2" and "0" smooshed on for me surrounded by a sea of

other colorful little birthday cake candles. Except, they weren't regular birthday cake candles. They were trick candles that Willow had secretly picked out. We lit the candles and walked our creation to the living room where Willow was waiting for us as we sang a discombobulated version of *Happy Birthday*:

**"Happy Birthday to you, Happy Birthday to you..."**

Dad and I attempted to blow out the candles, but they kept relighting, despite our joint efforts to eliminate the flames. Willow laughed heartily with satisfaction, as her little prank had been successful. We laughed along with her—we always did at her lighthearted cleverness.

After enjoying our celebratory confection, it was time for me to head to my friend's house—she and I had planned a trip for my actual birthday on the following day. I gave my dad a big hug and wished him a happy birthday once more. I then knelt to Willow, who was too weak to move from her sedentary position on the couch. I





squeezed her gently as I reassured her that I'd be back in just two short days.

I did return from my trip in two days as I had promised, but Willow wasn't there. Well, her body was there, but she—the Willow I'd known and loved my entire life—was not. She had fallen into a comatose state. Within half an hour, a crew of EMTs had flooded our home, carting Willow out on a stretcher, and bringing her to the hospital once again.

Despite the Opdivo immunotherapy, which had done remarkably well at containing her inoperable cancer for the last three years, her tumor—that devious, unforgivable, and relentless cluster of cells—had managed to grow ever so slightly, just enough that it had disabled her kidneys from doing their job of filtering waste—causing the buildup to overwhelm her system and induce her body into a state of shutting down.

During her stay, Willow underwent *yet another* invasive procedure, resulting in a new array of tubes and bags that would remain connected to her for the remainder of her life. However, we got lucky this time: Willow woke up.

The doctors praised my dad and me for our fast action, since Willow's body had already begun to enter the early stages of sepsis. If any more time had passed, the doctors postulated that the damage would've been irreversible.

We took Willow home, and, within a few anxiety-ridden weeks, she came back to us: the Willow we knew and loved was once again restored with her signature wit and charm. Thankfully, I hadn't lost my closest confidant, and we were able to enjoy the remainder of the summer. The crisis seemed to have passed, so in a state of relief, we moved on. However, it didn't cross my mind that this summer may very well be our last one together.

With the days of summer waning, it was time for me to return to school. It was an exciting time of year, as always. I would be returning to my friends and a state of independence. But that also meant leaving Willow, and, for that, I experienced intense feelings of guilt. Slowly, her condition began to worsen once again. It wasn't uncommon for things to go south overnight; this I knew. One day, Willow would be her normal fiery

self, determined and full of drive. My dad would insist on me waiting for him to return from his flying lessons before going to the gym so that Willow wouldn't be home alone. She hated that. I can recall the way she would roll her eyes with annoyance each and every time. After he drove off, she would lean over to me and say:

"You know, I hate when he does that. I don't need a babysitter. You go to the gym. I'll be right here waiting for you. Just make sure you're back before your dad gets home." Despite her requests, I never left her by herself.

As soon as the next day, she could be consumed with lethargy, too tired to move or even speak. There was no controlling or predicting it, but with time, Dad and I learned how to roll with those gut-wrenching punches.

Knowing how the guilt of not being able to be there weighed on me, my mom offered to go over to my dad's house regularly to check on Willow and keep her company. Wednesdays became their "Girl's Day." Each Wednesday morning, I'd receive a text from my mom giving me the rundown of their planned activities for the afternoon. My favorite read:

*Hi Jocelyn! It's Wednesday!*

*Guess who I get to see today? You know it! :)*

*Willow told me how she wished she could go get her nails done like she used to, so I stopped by the store yesterday and bought her some press-on nails. I'm no nail tech, but I'll do my best to make them look good for her. I'll send you pictures of how it turns out!*

*Anyway, I love you! Have a great day, and I'll give Willow a big hug for you.*

*Talk to you later.*

*Mom*

Both my mom and Willow confided in me about how valuable their time together was. It made each of them feel special and loved. For Willow, it was the fact that she had someone, other than my dad or me, to spend time with—someone she could gossip over celebrity news with, someone to do her nails, and someone who made her feel a little more human—more than just a bed-ridden cancer patient. In a routine

filled with doctor appointments and infusions, my mom's weekly visits gave Willow something to look forward to, and, for that, I am eternally appreciative.

Since her diagnosis in December 2015, it was understood that her tumor was inoperable, because it had manifested dangerously close to her sacrum. Her doctors feared that the risk of paralysis and loss of motor function would be too great to attempt surgical removal. So, the next best approach was to shrink the tumor or, if not shrink it, at least contain it and prevent it from growing and/or metastasizing using various treatment regimens—regimens that took an incredible toll on Willow physically, mentally, and emotionally.

Willow had gone through radiation, chemotherapy, immunotherapy, and multiple operations, including a colostomy. Radiation was the first treatment to be eliminated as it ultimately resulted in more pain than progress. Chemotherapy made her lethargic, weak, and intensely sick. However, a ray of hope arrived with the immunotherapy drug, Opdivo, which yielded beneficial results alongside the fewest side effects. Willow stayed on Opdivo for roughly three years.

We grew complacent, thinking we had found the silver bullet to the vampiric cancer that threatened to consume her. But eventually, the tumor stopped responding to the drug and, despite all efforts, began to grow. Willow, once again, got back on the treatment rollercoaster and she and her team of doctors decided to give chemo another shot.

With time, I was able to navigate Willow's condition via texts with my dad—and sometimes even Willow herself. On her good days, we talked and texted constantly throughout the day. On those days, she was my Willow, the competent funny woman I knew and loved so much. She followed the conversations. She provided witty banter with perfect spelling and complete sentences. But I could tell when she was getting bad again, as she would either text me gibberish or fail to respond altogether. It was a relief that usually these bad spells didn't last long. And Thanksgiving break was just around the corner. I'd be home again.

I remember how excited she was for me to come

home for the holidays. She texted me every day during the week leading up to my trip home—just to make sure I was still able to make it. I assured her I wouldn't miss it for the world.

Knowing what I knew, I understood that Thanksgiving would be different than it had been in the past. That there would only be only the three of us instead of a house bustling with family and friends. That Willow wouldn't be scurrying around the house cooking 10 different things at once with effortless grace, somehow managing to never ruin a dish like some sort of magician.

And I was okay with it, honestly. I felt like that made the occasion more special and memorable. I took over the cooking as Willow sat on the opposite side of the countertop, directing me on how to prepare all of her holiday specialties. I'm no chef; I had no idea what I was doing, but we just laughed and hoped for the best. Each time I finished a dish, I'd have her taste-test it to see if it earned the Willow seal of approval. She applauded everything I made, but I knew it was nowhere close to what it would have tasted like if she'd been the one cooking. If there was one consistency this Thanksgiving, it would be my dad spending the day on the couch, watching football, being absolutely no help.

After Thanksgiving, I returned to school, and things were hectic as usual at that time of year, with the semester set to end in a few short weeks. Despite finals and projects, I always made time to talk to Willow. She'd text me daily, wishing me luck on my upcoming exams or seeing what I got in my advent calendar as we counted down the days until the end of the semester and Christmas.

The night I returned home from school, I stayed at my mom's house, since I had to test negative for COVID-19 before I could be around Willow. I sent her a picture of my negative result, and we talked about how excited we were to see each other the next day.

Much to my dismay, when I arrived at my dad's house the next day, that excitement instantly evaporated. He told me that Willow had once again fallen into a disoriented state.

I shuffled up the stairs to find Willow in bed with

that same blank stare into nothingness. Over the next few hours, it became clear that she could no longer speak in complete sentences and could only muster enough energy to mutter single words over and over. My dad and I had to guess what she was trying to tell us.

Willow did not recognize my dad either. As he lay in bed next to her, she kept repeating:

"My husband? My husband? My husband?" as my dad anxiously tried to assure her that he was right there next to her. But she would look directly at him and simply ask: "Where?"

We sat in silence for what seemed an eternity. I concentrated on staring into the carpet, examining the individual fibers of fabric in hopes of distracting myself from crying. It didn't work.

My dad and I, unsure of what to do, remained silent. Willow slowly raised her arm and pointed at me. She weakly repeated one word: "Shot. Shot. Shot."

My dad and I looked at each other, bewildered.

She said it again: "Shot." Then, with her eyes still fixed on me, she said: "Maker's Mark."

Suddenly, we both understood, jolting my dad and me into a burst of laughter through our tears.

Just four days earlier, I'd texted my mom, dad, and Willow excitedly reminding them that in exactly six months it would be my 21<sup>st</sup> birthday, a milestone I'd been looking forward to for ages, because I was the youngest of most of my friends. Willow especially knew how eager I was to reach this birthday milestone. Before she got sick, we'd planned on taking a girls' trip to Paris, where we'd sip on fancy wines and indulge in as many cannolis and cups of gelato as our stomachs could handle. I hope to make it there one day and do everything we talked about, for her.

In that instant, my dad ran downstairs to grab the bottle and three shot glasses. This was not just any bottle of bourbon, though. This was Willow's special bottle. This is the bottle that Willow had personally filled and dipped in the

signature red wax during her trip to the Maker's Mark distillery in Kentucky years before she met my dad, and long before I was born. She'd told us on numerous occasions that *that* bottle was "off limits," because she was waiting to open it for a "special occasion."

This. This moment. Her lying in bed, losing her grip on reality, life, and her battle with cancer, slowly but also all at once, was it—that special occasion.

Returning with the unopened bottle and the shot glasses, my dad held it up for Willow to see. She mustered a slight smile and a faint nod. He pulled apart her red-wax masterpiece and poured each of us a shot. Willow held her glass with both of her shaky hands and was the first to raise it as if she were giving a toast, her eyes still locked on me. My dad and I followed suit, raising our glasses, and exclaiming:

***"Cheers!"***

My dad and I took the shot like it was apple juice. He looked at me in a puzzled manner as if he were thinking: "*How did she take that so well?*" Willow did her best but was obviously struggling. My dad snapped out of his confused gaze and rushed to help her, tilting the glass to Willow's mouth so she could consume her alcohol in baby sips. Her face changed to show us a glimpse of Willow, our Willow, who was satisfied with what had just transpired.

My dad left the room to take the glasses down to the kitchen sink, leaving Willow and me alone in the bedroom. I sat next to her on the very edge of the bed, making small talk, even though at the time I wasn't completely sure she was comprehending or even listening to me.

I held her hand and began to say goodnight, as it was getting late, and I knew the both of us needed our rest. But she interrupted me, grabbed my arm, and uttered her first complete sentence of the evening: "Please don't leave. I'm scared."

I scooted onto the bed beside her. "Why?" I asked, "What are you scared of?" She looked as if she was going to say something else, but instead, tears began to stream down her face.

"What's wrong?" I continued, lost in concern, and not knowing how to help.

"I'm afraid—afraid to go to sleep." She hiccupped between tears.

"Why?" I prodded, even though I had an idea of what she was thinking, I just did not want to believe it. She remained silent for a moment as if she were thinking meticulously about what she was about to say.

"I'm afraid I won't wake up." She burst into another bout of tears.

At that point, I had no more questions. My heart shattered hearing her words, and all I could do was bury my head in her chest and cry with her.

I'm not sure how, but somehow, eventually, I collected myself enough to leave the room, assuring her that everything would be okay and that I would come to see her bright and early in the morning so that we could open the next day's advent calendar slot together.

As usual, Willow was right. She didn't wake up the next morning. In fact, she never woke up again.

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The next two weeks were spent in the hospital. Initially, the doctors conducted a slew of tests and had her hooked up to an unfathomable number of monitors.

One of those many monitors indicated that her O<sub>2</sub> saturation was dangerously low. One night, sometime after 1 A.M., my dad and I were sitting in that tiny hospital room in silence, our eyes fixed on that one monitor, watching as the readout would drop and then climb back up, only to drop again. When her saturation levels dropped into the 40s, the machines started beeping erratically, prompting a surge of medical staff to swarm into the room.

After a few minutes of trying to get Willow's oxygen levels up, the attending physician pulled my dad aside, disregarding me. "Sir—" my dad stopped her, grabbing my arm.

"She needs to know what is going on, too," he

told the physician adamantly.

She nodded her head and continued on, telling us that our final option was to intubate Willow.

My dad dropped his head in defeat. "No. I'm sorry. We can't do that," he responded shakily.

"But, sir, if we don't—," the doctor began.

"Willow told me no extreme measures, no more procedures, no intubation, no resuscitation. I'm sorry, but I can't let you do that to her, it's not what she would have wanted" my dad said with conviction, making good on his final promise to the woman he loved, while his eyes welled up with tears.

"I understand," the doctor replied. She sighed and then continued "Well, then if it is alright with you, we are going to remove her monitors. We will keep her on the lowest flow of oxygen, but, from this point forward, we're just trying to keep her comfortable."

My dad squeezed my hand, telling me it was okay. We looked at each other, and then at the doctor, nodding in agreement, and defeat.

Within minutes, the room had emptied out, leaving the three of us alone once again: Dad, Willow, and me. Just as it had always been, ever since I could remember.

From that moment on, I was scared to leave the room in case she'd pass, and I'd miss my opportunity to see her again and tell her all the things I needed her to hear. But she held on in that delicate state between life and death—a place we could not be certain we could reach her—for about two weeks. Dad and I spent Christmas and New Year's by her side in that hospital. I got to give Willow her gifts, even though I knew she would no longer have any use for them.

Then, of course, the day came when I had to leave to return to school.

"I can stay another day or two. Really. It's okay," I insisted to my dad.

"No. You need to go back and get settled in. You



know Willow would want you to be there," he reassured me.

I procrastinated in that hospital room for as long as I could. I didn't want to leave. I didn't want to leave because I knew for certain that this would be my last time seeing Willow. My dad began to usher the nurses out of the room and then followed himself, but not before telling me: "Take as much time as you need. I'll be right outside whenever you're ready." He closed the door behind him, leaving just the two of us. Me and Willow, two peas in a pod.

I sat down in the chair that was already set up next to the bed. It wasn't close enough, so I scooted it even closer. I sat there in silence for a few minutes, trying to gather my thoughts. I wanted to make sure I didn't forget anything I wanted to tell her. I held her hand and watched her take small, shallow breaths. As I watched her, I thought to myself: "*How unfair. Willow was the most selfless person, who spent her entire life giving to others, putting everyone else first. She is the last person who deserves this. Why her?*"

Finally, I was ready to speak.

"First of all, I want to say thank you. Thank you for everything you've done for me and Dad. Thank you for loving me like I was your own since day one and for being my mom, when my real mom couldn't be. I am who I am today because of you. I hope you know that. If there's one thing

that I know, it's that you are the last person who deserves this, yet you've handled each and every obstacle with grace, and you've become a symbol of strength in my eyes. I know you're worried about Dad and me, but you need to put yourself first for once. We'll be okay—somehow. We'll figure it out, and we will have each other. I just want you to know that it's okay, and you're allowed to go. Thank you again for everything. I love you forever."

Willow passed away peacefully in her sleep later that afternoon, shortly after I arrived back at school. My dad had called to tell me.

At first, I was grief-stricken. *Who am I going to talk to when I'm having a girl problem? Or even worse: a BOY problem? Who am I going to send this funny dog TikTok to? Who's going to tell me what temperature to set the oven to when I'm trying to bake something? What am I supposed to do without Willow?*

With time, this state of grief slowly shifted to relief. No, not in the sense that I'm glad she's gone. I miss her and think about her every day. But I now know and can accept that although she is no longer with us, she's free of her pain and suffering. And I've come to realize that when you truly love someone, the last thing you want is for them to be hurting, even if the outcome ends up hurting you.

My dad's birthday and mine are still one day apart. He's still the 13<sup>th</sup>, and I'm still the 14<sup>th</sup>, but for the sake of simplicity, we still like to say we share. This year's birthday, however, wasn't like last year's. It will never again be like it was last year or the year before. With time, I've begun to realize that it's okay. I know that Willow is now somewhere safe, where she's free from all the unimaginable pain that she courageously endured, free from the endless routine of doctor's appointments and infusions, free from the countless rounds of treatment that destroyed her body more and more with each dosage, and free from the disease that ultimately stole her spirit—and stole her from us. I had my moments of spitefulness, but I'm no longer bitter or angry. Willow was simply too pure of a spirit for this intensely flawed world in which we live and wherever she is now, I choose to believe it's somewhere full of peace, love, and above all: comfort.

# A POLIO RECKONING

by Judith Moran

He came home early that day. I had just returned from school. It was May of 1954. I was in third grade. Why was he home so early? My father worked well into the evening most days. He went straight to the kitchen and took two tiny glass bottles from his black leather bag, placing them on the shelf inside the refrigerator door. “What’s that?” I asked him. He said it was a new medicine that needed to be kept cold. Dad often brought drugs home from the hospital, where he was a surgeon, to keep on hand for when my brother Fred and I got sick. My parents kept them and other medical supplies stored in the kitchen.

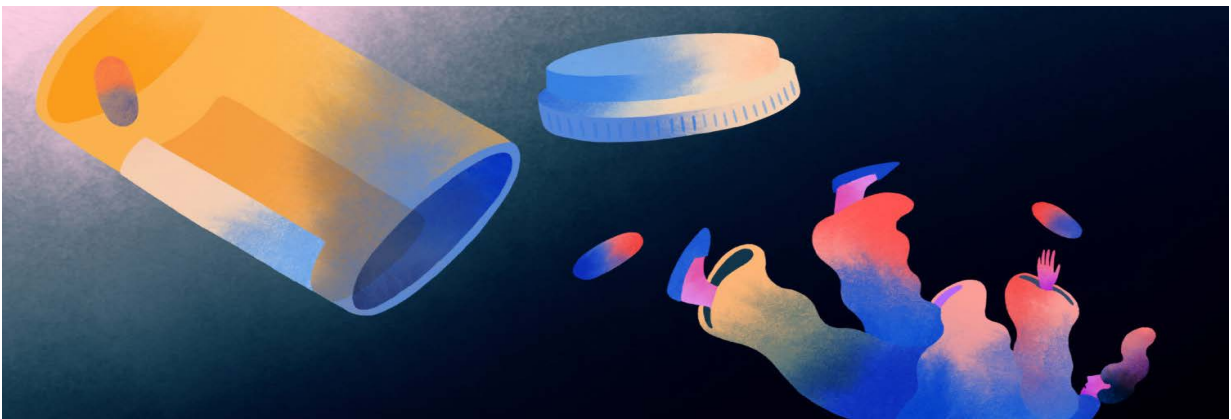
Dad said the medicine was like the shots Fred and I got at Dr. Finnegan’s office—the ones that kept us from getting whooping cough and tetanus. This one would keep us from getting polio. I wasn’t afraid of shots, but polio was scary. I’d seen grainy black and white footage of children in TV advertisements to raise money for The March of Dimes. The children, polio victims, used canes and wore braces on their legs. They weren’t marching, though, just hobbling along straining to remain upright. And some were confined in long metal cylinders—iron lungs, I would later learn. I tried not to think about what that would be like; I had claustrophobic nightmares as a child.

My friend, Garance, had gotten polio. Her legs were paralyzed. She had to wear leather leg braces and use two metal canes, just like the

children I’d seen on TV. I could see the effort it took for her just to stand up—her mouth clenched, arm muscles drawn up as she bore down on the canes on either side to steady her. And when she walked, her gait was stilted—her legs splayed outward. It reminded me of how the Tin Man walked in *The Wizard of Oz* movie. I tried not to notice. I didn’t want her to feel bad.

Garance lived in the house behind ours. I’d walk through an opening in our backyard fence to play with her. She never came to our house, although it didn’t occur to me then that she wouldn’t have been able to navigate the pathway through the fence, obstacle ridden as it was with stones and protruding tree roots.

Once, Garance took off her braces just to show me how heavy they were. We were playing with dolls on the rug in her bedroom. I couldn’t play jump rope, ride bikes or play hopscotch with her as I did with my other friends—her limbs were too weak and burdened with braces. The braces were made of leather—thick brown straps with buckles that encircled her calves and thighs. There were red spots on her legs where the straps had chafed them. She handed me one. I felt the heaviness and the moisture that had collected on the inside of the leather band. Garance said that the braces made her legs sweaty. She seemed relieved to be free of them, if only for a short time. As she struggled with replacing them, her father walked into the room. He was angry, his lips drawn into a grimace at having to help her with the braces. I felt complicit



in Garance's misdeed—sorry that she had gotten in trouble on my account. And yet, the incident made me realize that the braces affected her daily life in a way I hadn't considered. Besides the discomfort and limited opportunities for play, getting dressed for the day was no routine matter, as it was for me.

Dad gave Fred and me the polio shots that same afternoon as we sat on the bed in my bedroom. I put up a brave front when faced with needles; I willed myself not to flinch. My brother was less inclined. Dad and I had to coax him from underneath the bed. Fred was only six; he didn't understand polio as I did, having witnessed it firsthand as Garance's friend. He finally relented. I was relieved to have the shot business over with—spared from the braces, canes, and the iron lung. I thought of Garance; the shots wouldn't help her. And I worried about my other friends who might get polio. They didn't have dads who could bring the vaccine home from work and give them their polio shots. Would they get them in time?

Fast forward ten years. I had a summer job as a nurse's aide at a local hospital. I wanted to become a nurse. The hospital had once been used exclusively for polio patients—children mostly. A few of them remained. By then, they were teenagers like me. I was assigned by the head nurse to bathe one of them—a boy. "He's in an iron lung," she said as we walked to his room.

I stood at the threshold for a moment taking in the scene before me. I was terrified, curious, and distressed all at once at what I saw. There it was, the iron lung—the thing I had seen on TV years ago. I recall nothing else about the room save for the stark white walls. The "lung" looked like a sewer pipe, encasing the boy's entire body—only his head was visible. The machine heaved and sighed, like a giant lumbering beast. "That's the sound of the machine helping the boy to breathe," the nurse explained. She showed me how to remove him from the cylinder for bathing—a stretcher on wheels detached from the outer casing. "Don't keep him out too long," the nurse cautioned. I wondered what that meant. Would he die? After introducing us, and before I had a chance to question her further, she left me to care for him, closing the door behind her. I tried to remain calm and appear competent, although given the circumstances, I was anything but that. I was eighteen,

never having worked in a hospital. I was left unsupervised to bathe a boy dependent on an iron lung to breathe. The only instruction was to do it quickly.

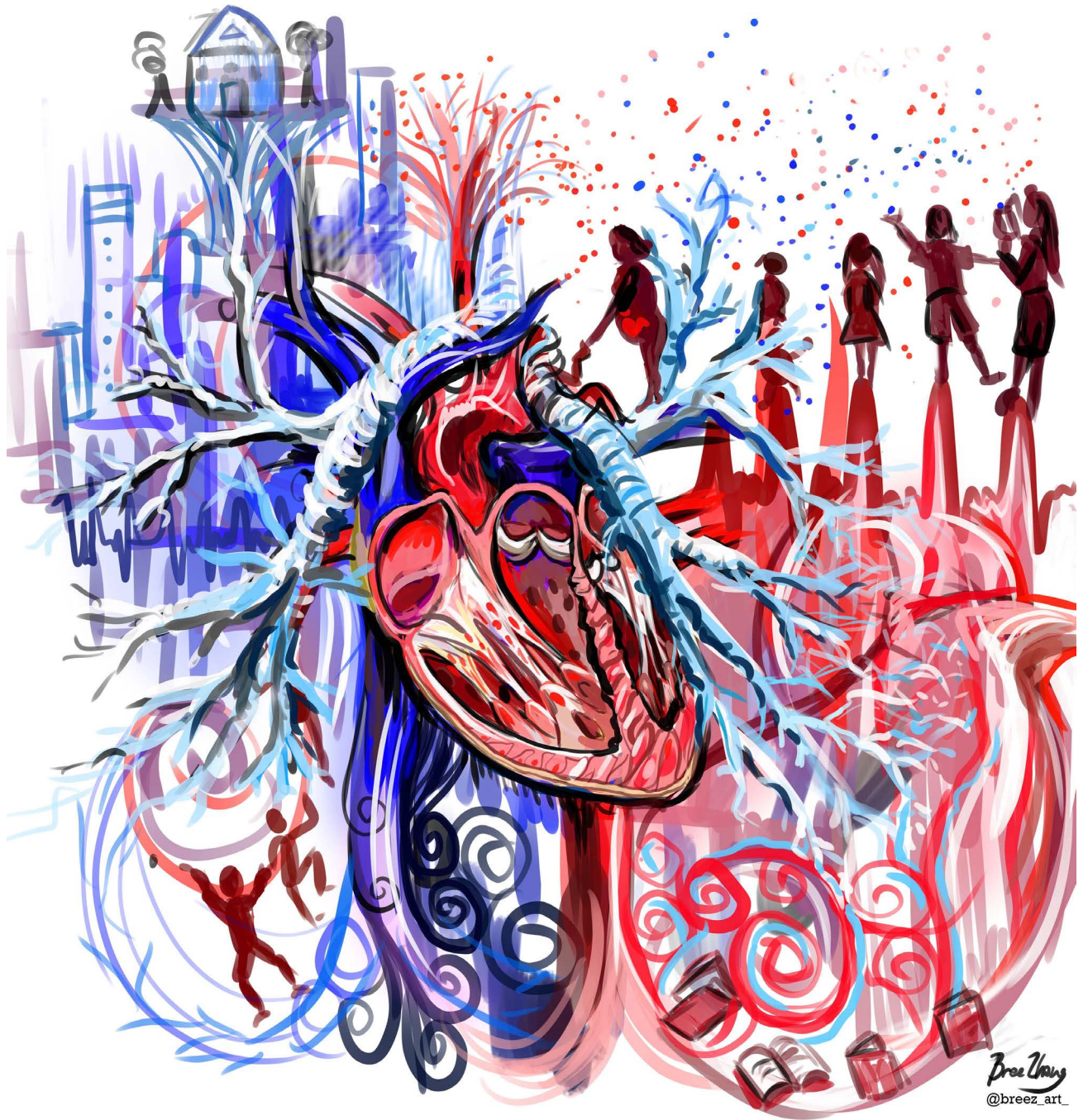
I carefully pulled the stretcher from the iron pipe exposing the boy's body—a white hospital gown was draped over his torso. His wasted legs were exposed—pale and bereft of muscular flesh. The pallor of his limbs matched that of his face damp with perspiration. His black hair was shaggy, sweat-soaked, and matted. He needed that bath for sure; he smelled bad. And then I faced another fear, I'd have to remove the gown and he would be completely naked. Under different circumstances, I might have met him at a summer beach party. He would have been muscular and tanned by the sun, wearing a bathing suit. But for this situation—a naked boy just my age, confined in a machine without which he couldn't breathe—I was totally unprepared.

I wonder how I managed it all, the fear it inspired—the boy would stop breathing—or the awkwardness in making conversation. I don't remember what we spoke about as I sponged his body. I recall that he seemed at ease talking to me no matter that I had removed his gown leaving him stripped bare. I was embarrassed by his nakedness and reminded of the claustrophobic anxiety that had haunted me since childhood with nightmares of being in a confined space. He was imprisoned. I could go home at the end of the day. If not for the drug my father had injected into my arm that could have been me.

In the fall of that year, I entered nursing school. It was likely predestined given that I'd grown up with drugs, needles, and syringes stored in the kitchen. I became a registered nurse four years later. Never again did I care for a patient in an iron lung. The polio vaccine had been given to legions of children by the time I graduated—iron lungs had been replaced with ventilators, a less confining apparatus. As I write this, the polio virus has re-emerged in New York City where I live now. The drug that saved me has become controversial; its safety called into question. The polio resurgence is an unfortunate consequence. I am troubled by this turn of events—that children may suffer unnecessarily without a vaccine to protect them. The boy in the iron lung I cared for those many years ago had no choice.

# A THANK YOU TO OUR DONORS

by Bree Zhang



Bree Zhang  
@breez\_art



# ARTIST STATEMENT: A THANK YOU TO OUR DONORS

by Bree Zhang

What does it mean to cut into human skin?

On our 1st day of anatomy during orientation week, we went to lab and skinned our cadavers. I assumed that all medical schools started dissections early like Columbia. But recently, after conversing with medical students in ICEP (International Collaboration and Exchange Program), I learned that we all treat anatomy so differently.

Some schools don't do cadaver dissections at all. Others wait until year 2 to begin. Other schools, like Yale, do dissections in year 1, but before starting anatomy, they first spend their time on a humanism block. They learn of their donor's occupations and have opportunities to reflect and honor their donors' humanity through art and writing. Perhaps this makes the 1st cut harder. Slicing into skin is much more difficult when you've thought about the origins and hardships of that skin. But perhaps it improves the intentionality of each moment in the lab. Makes them appreciate the knowledge more.

After my conversation, I started thinking about

my donor. Who was she before? A mother? A daughter? A friend? A coworker? How is her family doing now? Do they know how much she's given us? Do they know that the whole dissection process renders the original body unrecognizable?

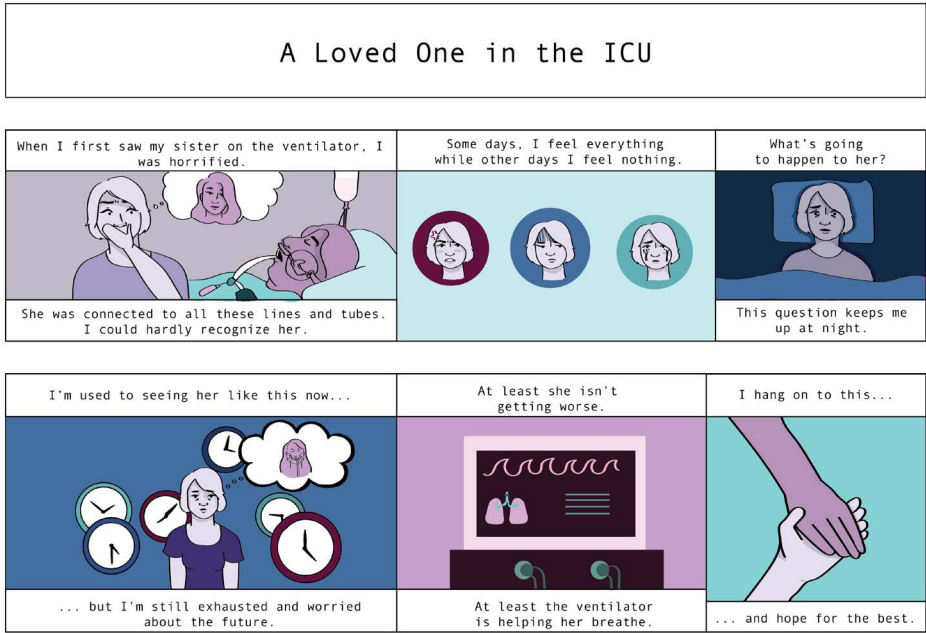
And so, I return to my medical illustrations of Block 2. Previously, I drew the heart and lungs to help me study anatomical structures. Now, I reimagine my "study drawings" to honor our donors not just as cadavers but humans who once had beating hearts. Sometimes it takes "zooming out" to see the full picture. To understand the comorbidities and the weathering that explain cardiac valve replacements, blackened lungs, calcified arteries, cirrhotic liver. That's why dissections are so beautiful because they allow me to hold so many feelings at the same time: excitement, intrigue, gratefulness, but also sadness and mourning.

This artwork is a dedication to our donors. A thank you. A promise to learn the most as possible—because that's how I repay them.



# IF YOUR LOVED ONE IS IN THE ICU

by Anasemi Owate-Chujor



# AT THE DOCTOR'S OFFICE, SE HABLA ESPAÑOL.

by Ashley Yobeth Hernandez-Gutierrez



# THE TRANSITION TO ADULTHOOD FOR CHILDREN WITH DISABILITIES

by Sirena D’Orazio

Thump, thump, thump. Nineteen-year-old Emma’s feet hit the ground at a steady pace of 0.8mph. The treadmill hums softly as Emma’s heart rate increases—133, 134, 135, until it settles at 137. “She expends more energy than us,” Michelle, an occupational therapist at the children’s hospital occupational therapy clinic where Emma is a patient, explains. She hovers by the treadmill, ready to help Emma at any moment, “This is like WD40-ing her joints after winter!” Emma finishes her five minute warm up and makes her way over to a padded table in the clinic’s gym. Sweating, her cheeks pink with exertion, she gladly reaches for her *Encanto* water bottle.

Though Emma is legally an adult, she still receives treatment for her spina bifida and hydrocephalus in the pediatric clinic. “They’re not progressive, but she’s still battling the side effects,” says Michelle. Emma’s legs “get really tight” and she has to work extra hard to strengthen them. She also has communication challenges and low cardiovascular stamina.

“We treat patients until they’re 21,” Michelle says, “it’s really great because we’ve had Emma for a long time, and we’ve gotten to know her.” Most adolescents without disabilities grow in independence as they transition to adulthood. However, for adolescents with disabilities, like Emma, this is simply not possible. No matter how far Emma progresses, she will need assistance her whole life. Her cognitive disabilities are such that she needs others to help make informed decisions on her behalf. Without a good support system to make these important decisions, adults with disabilities slip through the cracks. And, unfortunately, if they don’t already have family or friends who are willing to help, there

aren’t many external resources to provide them with good support systems.

Dr. Pei-Chi Wu, a developmental behavioral pediatrician at Hasbro Children’s Hospital’s Children’s Neurodevelopment Center, says that her patients “just disappear into the world,” when they become adults. “There’s no equivalent for my profession for adults,” she says, “Families try, but only a minority find a team to support their [adult] child.”

Emma is one of the lucky few who have a good support system in place. Even still, it’s challenging for her family to keep on top of all the services she requires. “Emma’s sister takes her to everything,” Michelle said, “because she speaks English, but Emma’s parents don’t, so it’s kinda difficult for them, ya know?”

Emma finishes her one-legged bridges, and Michelle transitions her to the next core-stabilization exercise: “mermaid planks!” Emma has trouble understanding Michelle’s description of the exercise, so Michelle decides to do them with her. She hops up onto the table, faces Emma, tucks her knees to the side, and lifts her hips.

“Where’s my sister?” Emma asks abruptly. Michelle says, “She’s gone. She left.” A smile slowly spreads across Emma’s lips, “Hey!” she says. She knows her sister would never leave her. “Of course she didn’t leave!” Michelle said. She brushes her long, thin braid out of her face, “She’s getting your splints!” Emma’s sister spends



an hour dealing with the insurance agency before she can finally pick up Mealnie's splint. She knows Emma needs it to retrain her ankle to stay straight while she sleeps at night.

Emma's sister is a large part of the reason Emma is doing so well in spite of her disabilities. "One of the most important things is that they do their exercises at home, especially for Emma," Michelle said, "Her sister is a great motivator; she does a good walking program with her, and she takes her to basketball," Michelle says. She also helps her do yoga, which she loves.

Aside from keeping up with their health, adults with disabilities often struggle to find a job that they can do well and enjoy. There is no system set up for them to find such a job, and they are often incapable of searching for one themselves. It usually falls to the parents or family members to scope out a good situation: usually a part-time job working for a family friend or a low-commitment job where they can work from home. But every disability is unique, and the typical work environment isn't adaptable for all disabilities.

While Emma is on a break from exercises, Michelle asks, "Are you in school right now Emma?" Emma takes a minute to gulp down her water and processes the question. "No school," she says. Eventually Michelle learns that Emma would graduate high school in a week but was already done with classes. She also learns that Emma had already started her new part-time job. "Do you like it or hate it?" Michelle asks. Emma pulls at her faded *Frozen* t-shirt, then swats her dark brown ponytail away from her face. "Like it," she says.

...

Dr. Karen Cammuso, the Clinical Director of Bradley's Verrecchia Clinic for Children with Autism and Developmental Disabilities, says that most resources to help adolescents with disabilities transition to adulthood were halted for two years during the pandemic. They graduated high school, and then "had to wait at home for their vocational opportunities to start." Many have "low intellectual abilities," so the job opportunities they were offered before the pandemic were their only prospects. Uncertainty about the future caused mental health challenges for all young people during the pandemic, but young adults with disabilities were particularly affected.

Parents didn't know what to do. One minute their children were ready to begin the next phase of their lives and then, they were stuck at home 24/7, in need of full-time supervision and care. Camusso describes one child who had four different caretakers. "Each lasted only one to two weeks, for two to three months total." Parents, many of whom had full-time jobs themselves, were simply unprepared to take on the additional role of supervising their adult children. And those who were able to hire caregivers found that the caregivers were insufficient because they didn't have the experience to handle their child's particular needs, especially amidst the uncertainty and isolation of the pandemic.

...

When asked what the options are for adults living with autism, Patti Gay, the owner of Two Can Art, with her autistic adult son Noah replied, "Dismal." She sighed, "My resources are good now, but I had to fight for them."

Gay started Two Can Art as a way to support Noah and raise awareness about autism. He contributes to support himself and she manages his life and makes sure the business is running smoothly from the comfort of her own home. She has an in-house art studio where Noah makes different textures with paint. Gay layers these textures, and makes images out of them. She puts them on mugs, t-shirts, bowls and various other objects, and sells them online.

Gay has set up a unique situation for her son, and he is doing well. She was trained in Applied Behavioral Analysis (ABA) therapy, and developed a program specifically for Noah, to teach him self care skills. "We try to add new things to his repertoire to make him a participant in the household." He also has the support of a regional center, where he does a day program in conjunction with his ABA.

The more involved a parent is, the better the outcome for adults with disabilities, says Gay. Lucky for Noah, Gay has long been a strong advocate for her son's needs. When asked what her experience was like trying to access services for her son growing up, Gay replied, "Hell." She said, "It was a nightmare- we fought tooth and nail, we even took the school district to court."

She explained that his local public school wasn't

providing him the services he needed, so she took them to court and won. However, even after the lawsuit, the school still didn't provide satisfactory services, so the whole family moved to Santa Cruz, where there was a better school district. Noah went to school one day a week, and Gay had to hire someone to come and observe him, to document his needs. "We needed an extensive paper trail to get him services."

After all of that effort, a new program director was hired, who "was absolutely horrible. He wanted to reverse [Noah's] goals to things that had been goals years before." Under the new program director, Noah had an increasing number of anxiety attacks and behavioral issues. The final straw was when Noah broke his leg at school because no one was watching him. After that, was when Gay decided to homeschool Noah.

All of these measures to ensure Noah's well-being would have been "impossible to do without the resources I have. You have to educate yourself- it's a lot of work and not everyone can do it," Gay says, "It's a full time job." Some adults with disabilities aren't so lucky- they don't have parents who are able or willing to take care of them for their whole lives. And if the parents aren't in the picture, adults with disabilities struggle. Gay says, "It has to be parent driven to be successful."

"My biggest worry is the future, when I'm not here anymore," Gay says. She explains that Noah is completely non-verbal, so it's difficult for people who don't know him well to understand what's bothering him when he's frustrated. She has the resources to set him up with a caregiver after she's gone, but will the caregiver be able to understand him? Will they have Noah's best interest at heart? These are questions that plague parents of adults with disabilities.

...

Noah and Emma are part of a subset of adults with disabilities whose families are able to support them. Not all adults with disabilities are so lucky. Although the state offers services, not all can access them. Jenna Nutting, the Vice President of Support Services at Crossroads Homeless Shelter, writes, "Adults with disabilities often fall through the cracks of the system and don't always have support to access the resources they need." She writes that many of

these individuals who would otherwise end up in a shelter use Crossroad's temporary housing program and wraparound supports. She calls for "sustainable funding from state and federal leaders" for their 'Health + Housing' program.

Kevin Savage, the Director of Developmental Disability Services at the Rhode Island Department of Behavioral Healthcare, had no comment on this statement but did say he would be willing to investigate a particular case of an adult with disabilities who was unable to access disability services. When asked about improving access for disenfranchised individuals, Savage said that the Rhode Island Department of Developmental Disabilities is working on more effective communication strategies, specifically "getting information out in English and Spanish," and for people who are "deaf or hard of hearing."

The biggest challenge to expanding access in his field is lack of personnel and resources. "Direct support professionals who work in a residential setting," says Savage, "require a level of gentleness and kindness" not expected in other jobs. "It's a highly skilled field that from a financial point of view wasn't valued at the level it needed to be." He says that in Rhode Island, we've made improvements in starting salaries "so that we can recruit people" but still need to increase salaries to reflect the higher skill level of more experienced employees.

When asked whether he thought Rhode Island was adequately supporting the needs of adults with disabilities, Savage said, "To the best of our ability, we are, but we're always going to want to be improving."

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# HEAD ORCHIS

by Simone Nemes



# FROM PATIENT TO PRACTICE

by Brynn Goggins

## Introduction

"I would say, it's a lot easier to forget that's a person when you haven't been in those shoes. It's a lot harder to forget when you have. You know, I mean, it's really almost impossible." Jennifer is an internal medicine physician currently working in student health. She is also a daughter, a mother (to three kids and a dog), a friend, a sister, and an aunt—my aunt. She was diagnosed with non-Hodgkin's lymphoma in July of 2006, when she was 41. Thankfully, her story did not end there. She has been in remission since December 2006, for about 16 years. Nonetheless, the impact of this illness remains.

Jennifer's story provides an interesting perspective on what it means to be a patient who knows medicine and a doctor who understands illness. Her experience demonstrates that when physicians become seriously ill, their illness—beginning with their diagnosis—is shaped by their medical knowledge and identity as a physician. Subsequently, their career as a physician is shaped by their illness experience, and the aspects of medicine that were revealed to them as a patient. There is currently some literature that helps us understand what it is like for physicians to experience an illness. However, there is little literature that tells us how these physicians'

practices change when they return to their careers. This paper will work to address this gap in the literature by gaining an in-depth understanding of Jennifer's experience with cancer and how it ultimately changed the way she practiced medicine.

## The Diagnosis

Jennifer's diagnosis was not a "normal" one, mostly because she somewhat anticipated it from the day she discovered a lump in her groin, and possibly even several years before that when her left-sided sciatica began. Her first thought after discovering this lump, that "maybe this is just a reactive lymph node," was perhaps typical: one any lay person might experience. But, remembering a skin lesion she had previously gotten removed in a nearby area, her second thought was "Fuck. That was not a benign skin lesion. I have melanoma and I'm dead. And I've got three little kids." Anyone may have quickly jumped to a thought as morbid as this one. As a physician, however, Jennifer carried a detailed mental repertoire of all the possible pathologies her symptom could be. Several years before this she had been having intermittent left-sided sciatica. A few weeks after she discovered the lump—but before she had it removed and sent to pathology—the sciatica got very bad, much more severe than she had ever experienced.



She explained an intense feeling in her gut that these two occurrences, so close together, were “more than a coincidence.” She wondered if she “had some malignant tumor in her pelvis or something that was pushing on a nerve,” citing Occam’s Razor—an idea in medicine that the simplest, most unifying explanation is the right explanation—as a reason to believe this lump and sciatica were related.

While any person might be able to dismiss their anxiety as unfounded and premature, Jennifer’s concern was grounded in a deep familiarity with the human body and, thus, harder to dismiss. This medically-informed, anticipatory anxiety continued when she received the actual diagnosis. She described how the phone call confirming that her fear of a cancer diagnosis was in fact correct made her “gears crank in a very different way than somebody who doesn’t know medicine.” When physicians receive a diagnosis, their understanding of what the future process will entail—the tests, treatments, and side effects to come—is much more comprehensive than that of someone without the same medical expertise. As described by Arthur Kleinman in *Illness Narratives*, the term “disease” alone can not encompass the full experience of illness (Kleinman, 1988). From the beginning, Jennifer understood that this diagnosis meant more than a disease, and her life would change significantly as a result. An MRI soon showed her that there was, in fact, a malignant tumor next to her spinal cord that was pushing on a nerve; the cancer had spread far beyond the lymph node in her groin.

## The Illness

This duality of both being treated by a physician and serving as a physician made it extremely difficult for Jennifer to take on the role of a patient. In his article “Between Two Worlds / Physicians as Patients,” R.A. Hanh explains that, for physicians, “becoming a patient means loss of control, helplessness, and assumption of a passive role,” and he enforces the difficulty of physicians to “surrender” to their doctors (Hahn, 1985). For Jennifer, her medical knowledge acted as both a blessing and a curse. After her first round of chemo, Jennifer ended up in the hospital. Her gut had stalled and nothing would move. To relieve the pain, she received a continuous, intravenous

fentanyl drip. Once again, her fatal fears flushed in: “Fuck. I’m gonna die of an opioid overdose in the hospital.” As a physician, she knew this was a risk. Fortunately she knew how to mitigate this risk, though it caused her to be hyper-vigilant about the treatment. As she lay in the hospital bed, she carefully watched the IV and did the mathematical calculations of the rate of the drip to ensure that she was not getting “some decimal point off the amount that [she] should be.” Only after confirming that the calculations were sound, and scanning the room for Narcan, was she able to fall asleep. Months later, after her chemo treatment was completed, Jennifer’s oncologist recommended they harvest stem cells from her—a process that notoriously causes blood cells to get “out of whack.” After finding out her platelet count, which was “way below the threshold where people will spontaneously bleed into their brain,” Jennifer called her best friend and asked to spend the night with her. Her kids were with her ex-husband, and she feared that if she spent the night alone in her house, she would be dead by morning and no one would know. At the time, she had no idea that her oncologist was unphased by her platelet counts. He had been in the speciality long enough to know that they would be resolved by the next day. Jennifer, on the other hand, did not know that, given that in her field of internal medicine, those platelet counts would sound the alarm. Jennifer knew too much about medicine to experience the bliss of ignorance but not enough about the specifics of oncology to understand when she did not need to be worried.

Being a patient was not only a difficult role for Jennifer to ease into, but it also created a disconnect between her situation and her identity. Already, it was difficult for Jennifer to grapple with the idea of having cancer because throughout her entire life a major part of her identity was being a healthy person. In his interviews of numerous physician-patients, Hanh too found that for one man, “[h]is youth, apparent good health, and his sense of strength and competence have fostered his belief that serious illness—asthma, cystic fibrosis, diabetes mellitus, and cancer—happened elsewhere (Hahn, 1985).” On top of this internal identity struggle, she now had to deal with being the patient in physician-patient interactions, stating that as a physician “even though you know [being a doctor and being a patient] are not mutually exclusive, you still kinda cruise along not really thinking about being on the



other side of the table most of the time.” From this multidimensional disconnect that she experienced, Jennifer gained empathy for the complexities that come with being a patient.

## The Spark

Jennifer’s very first oncology appointment revealed the stark contrast between the various types of treatment patients encounter in the healthcare system: her oncologist was “amazing.” For the first half hour of her appointment, he did not once mention the reason for Jennifer’s visit. Instead, he asked her about herself, about her work, her kids, and her family, “de-escalat[ing] anything that [she] might have been feeling before he started getting into the nitty gritty.” At the end of the appointment however, as Jennifer sat with the receptionist booking a long list of future appointments, the receptionist continued taking several other calls—forcing Jennifer’s needs to be put on hold, and leaving her feeling invisible:

To her, this was something she did all the time. But I’m sitting there in this chair, as a physician, with a new cancer diagnosis, going ‘what the F.’ You know, she’s trying to schedule me, and taking all these calls, and having these conversations right in front of me. At one point, I must’ve had a funny look on my face, and she looked at me and she said ‘Are you okay?’ And I just said ‘No. No, I’m not okay. I’m... I’m here.’

Just earlier that morning, Jennifer had received the call confirming she had lymphoma. Her best friend, a fellow physician, had called this oncologist who agreed to squeeze Jennifer in during his lunch break. The oncologist understood the significance of this day and this appointment. He handled it—and Jennifer—with care. The receptionist, however, did not. To the receptionist, Jennifer was just another cancer patient with a list of appointments to schedule.

## The Career

This specific appointment, added to her already-complex illness narrative, made Jennifer hyper-aware of being recognized as a person versus a patient. Viewing someone solely as a patient

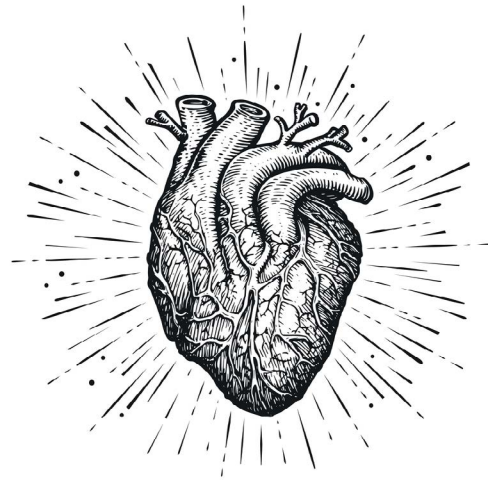


makes it easy to forget they have a life beyond their disease and doctors appointments.

This is known as the “medical gaze,” defined as “seeing a ‘case’ or ‘condition’ rather than a human being,” and is extremely common among physicians (Davenport, 2000). The practice of employing this medical gaze is referred to as “gazing” (Davenport, 2000). In *Becoming Gods: Medical Training in Mexican Hospitals*, Smith-Oka describes how throughout their training, interns and medical students learn to depersonalize and objectify patients, and listen to their narratives with the sole intent of finding a diagnosis, rather than thoroughly listening to what they have to say (Smith-Oka, 2021). Jennifer was trained this way too. She recalled that everything at her medical school was “starch white coats,” “science, science, science,” and “data driven.” In Stevens’ article “From medical gaze to statistical person: Historical reflections on evidence-based and personalized medicine,” he explains how “statistics or ‘risks’ cannot tell us how to act” (Stevens, 2016). The data is often difficult to interpret, even for medical professionals, and many other factors need to be considered when deciding how to approach individual circumstances (Stevens, 2016). Jennifer described how a heavily science-focused training makes it easy to “use data to guide all your decisions” instead of “using data as a guardrail” to take each patient’s unique situation

into account when determining the best way to provide care.

Jennifer always understood that each patient requires personalized care, but it was not until after her illness that she gave herself permission to act on this even more and to “treat people in the way that [she] knew in [her] heart [she] wanted to.” From her own experience, Jennifer gained a deeper understanding of how important it is for patients to be treated personally and sensitively. As a patient herself, she did not want to be treated as a statistic. She wanted to feel like a person. Therefore, as a physician, she wanted to be one who made her patients feel like people, not statistics, and one who ensured her patients were treated with the holistic



understanding she knew they deserved. In Charon’s “Narrative Medicine: Attention, Representation, Affiliation,” she describes how physicians should provide care by taking the time to listen to the patient and understand their history (Charon, 2005). This practice, referred to as “narrative medicine” (Charon, 2005) and as “witnessing,” is the exact opposite of “gazing” (Davenport, 2000). It allows physicians to see the patient as a whole person, and therefore enhances the quality of care they provide. This is exactly what the oncologist did for Jennifer when he spent the first half hour of their appointment asking her about herself, not once mentioning the reason for her visit, and exactly what Jennifer so strongly sought to do for her patients. However, despite this overwhelming instinct, Jennifer was unable to provide this depth of care at the large practice where she worked as a primary care physician.

Regardless of how much they may wish to do so, Jennifer and so many other physicians are unable to apply narrative medicine due to the constraints of modern medical practices. As stated in Linzer’s article “The End of the 15–20 Minute Primary Care Visit,” “fifty-three percent of primary care providers report time pressure in the clinical encounter” (Linzer et al., 2015). The complexity of issues addressed in primary care visits has increased, leaving physicians to accomplish more tasks in these less-than-20-minute visits than ever before (Linzer et al., 2015). This results in “appointments in which fewer health care issues are addressed and depth of understanding is diminished” and

“time-consuming psychosocial determinants of health are left unaddressed” (Linzer et al., 2015). Appointments like these force the physician to pick and choose what they are going to address, which often ends up being the metrics—such as a high BMI, or an overdue pap smear—that are glaring at them from the patient’s chart, rather than the underlying causes of their disease—such as a lack of access to healthy foods or a nearby healthcare provider. Jennifer often found that, as a result of not being able to address all of a patient’s concerns in one visit, she was forced to ask them to schedule a follow-up appointment. However, these medical offices are often so over-booked that there is no capacity for them to schedule that follow-up appointment. Patients are left with unaddressed problems, and physicians are left feeling inadequate, forced to move onto the next patient, where the cycle will likely repeat itself.

Eventually, Jennifer moved on from the practice where she was forced to gaze, stating “the only way around that anymore is direct primary care, concierge medicine, or student health, or another niche practice.” Now, she has the capacity to witness. She chose to transition to student health, which allows for more time with and a more holistic approach to each patient. Because the college patient population is so focused, there is more availability in the schedule for patients to come back as often as they need. Additionally, because most of this population is young, the majority of them do not have to deal

with many multifaceted or chronic illnesses. So, when patients do come in with a complex illness, Jennifer has significantly more time to focus on them, listen to their narrative, and address their individual needs. She finally feels able to provide care in a way that more accurately reflects the thorough and compassionate physician she has always been, at a practice that allows her to convey a new level of empathy, instilled by her own illness experience.

## Conclusion

Jennifer's narrative speaks to a larger issue of the constraints of modern medicine, and can be used as a motivator for change in the medical system. Physicians who care about their patients should not have to cite their commitment to care as a reason to leave a position. Instead, they should be able to reflect it in their practice. This experience—what Jennifer learned from

her time as a patient and the ways in which she subsequently altered the care she provides her patients—can also be used as a guide to train other doctors to better empathize with their own patients. One should not, of course, argue that every physician needs to experience a serious illness to be able to adequately empathize with patients. One can, however, learn from the physicians who have—how their level of empathy changed and how they demonstrate this empathy to patients—as a way to teach other physicians who may not have gone through this experience how to provide this level of care. This crucial training extends beyond just physicians, back to the receptionist at Jennifer's first oncology appointment and to anyone people may come into contact with in the healthcare

system. As Jennifer emphasized, "From the clerk who's checking you into the ER, to the person who comes and picks up your trash out of your room... Anybody in that chain, whether they are clinical or not, needs to kinda just periodically have someone tap on their shoulder and say 'Remember you're dealing with people. To you this is just a flash in the pan but to them, this is their life.'"

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