***Introduction**: We are pleased to present the fourth in our series entitled "On Equity Story Slam". The following six essays were presented at the Department of Medicine Grand Rounds on January 11, 2024. The presentations were organized and coordinated by Lisa Skinner, MD, Program Director for UCLA Internal Medicine Training Program and Health Science Associate Professor of Medicine, Keith Norris, MD, PhD, Distinguished Professor of Medicine and Vice Chair for Equity, Diversity and Inclusion, and Alina Lee, Program Coordinator. To review the recordings of "On Equity Story Slam", please visit DOM TV, where recordings of Medical Grand Rounds are accessible. The specific link for each individual presentation from January 11, 2024 is included at the end of each submission.*

ON EQUITY STORY SLAM

"You Got This"

Marcella Calfon Press, MD, PhD

It was a Friday evening after a long week, and I was exiting the parking lot with a sigh of relief that the week was coming to an end. I couldn't wait to get home and see my wonderful husband and daughter. In the back of my mind, the lingering emotional strain of being on STEMI call was present- a feeling I know well having practiced interventional cardiology as an attending for more than 10 years.

As I turned the corner on Gayley Ave, I heard the familiar sirens echoing a nearby ambulance as it approached our Emergency Room (ER). Reflexively, I pulled over and quickly checked my email. My gut was right, it was an ambulance arriving with a patient suffering an acute ST Elevation Myocardial Infarction (STEMI). The Los Angeles Fire Department EKG transmission showed those familiar yet frightening inferior ST elevations that required our team to provide immediate reperfusion to an occluded right coronary artery that was calling our names.

I quickly made the U-Turn and reclaimed that old familiar parking space that has become my friend all these years. I walked to the ER at a rapid pace, my heart beating faster and my breath more shallow with that feeling of excitement, a tinge of anxiety, a respect for the challenges ahead, and a play-by-play checklist of critical steps and the potential scenarios about to play out.

As I approached the trauma bay in the ER, the patient appeared diaphoretic but awake and alert. His vital signs were acceptable, but not ideal. I could see a prior sternotomy and was immediately keen to see if any prior records were available to help me navigate his bypass grafts. Like a sponge, I began absorbing my surroundings - mapping out plans with the team of doctors, nurses and technicians around me with the hopes of moving him up to the cardiac catheterization lab as fast as possible. "Every minute counts" played like an old song in the back of my mind. At the corner of my eye I could see a woman standing anxiously, her eyes building up tears. She watched us with suspense and fear. I gave her a gentle nod hoping to provide her some comfort and reassurance…but my attention was glued to the man in front of me.

After confirming the brief history I had obtained from the team, I began to explain to him that he was having a heart attack. One of his arteries was likely to be occluded and that my recommendation was to administer some medications and bring him up to the catheterization lab for an angiogram and possible stent to open up the artery immediately. As he listened to me, I noticed his color more grey- at the same time, I could hear the now tearful woman speaking with the male ER attending… "Is there anyone else available to do this procedure?" she asked. "Dr. Press is on call and your husband will not survive if he waits for another cardiologist to open up the blockage." My heart sank. At the same time, so did his. The BP plummeted and his eyes rolled back. The rhythm was ventricular fibrillation. The crowd began CPR and like a well-oiled machine, the gears shifted in the hopes of bringing him back. Unfortunately, the rhythm persisted and the patient was rapidly placed on Extra Corporeal Membrane Oxygenation (ECMO). As my initial plan of revascularization adapted itself to the rapidly evolving clinical events, the patient was eventually transferred to the catheterization lab after informed consent was obtained from his wife. As I walked out of his room, it was as if the ER attending could feel my insecurity; my fear that maybe his wife was right…my mind was filled with thoughts. "If I am not able to bring him back, could one of my male colleagues have been able to...? Will his wife forever regret her decision to trust me with her husband's life...?" With a comforting smile and a hand on my shoulder, the ER attending said "You are the only thing standing between this patient and the ground… you got this". Those words still resonate with me today. It is the support of our colleagues that so often lift us up and provides us with the strength to face the inevitable stress and challenges of our profession. My feet felt lighter and I lifted my chin and gave him a big smile of gratitude.

Thankfully, with a talented fellow by my side and the combined expertise of the cath lab and ICU teams, we successfully re-

canalized and stented a complex and calcified native RCA that was 100% occluded. He was successfully cardioverted into a sustainable sinus rhythm and over the course of the next 24-48 hours, he was de-cannulated from ECMO. His wife was by his side- they smiled at each other. With a sigh of relief, they turned their heads towards me and together we smiled lifting the sense of impending doom and allowing feelings of relief and happiness to pour in.

The patient has remained under my care since then. His wife and sons are now my patients. His wife still thanks me for saving her husband's life and I am still thankful for the incredible team of doctors, trainees, nurses, technicians and staff that, as a team, resuscitated him and saved his life. I am also still thankful for the male ER attending who lifted me up that day and the trust that was eventually given to me by his wife and family. After all, they were able to set aside their doubts and let the care speak for itself. That doesn't always happen.

Telling this story today "On Equity Story Slam" has allowed me to reflect on my career as a female interventionalist. As the hairs on my head begin to shimmer with age, I embrace the privilege and responsibility I have been given to share my experiences with colleagues and trainees alike. Understanding that we all experience feelings of hopelessness, fear, and insecurity and that our profession is marked with an almost unfathomable responsibility to save lives or at the very least, never cause harm, is important. Knowing that everyone can and will make mistakes, but also understanding that some mistakes can be life-threatening, is a heavy burden for us all. The COVID-19 pandemic has unsurfaced rampant physician burnout which has led to high rates of depression among physicians. Those who are under-represented in our profession are at increased risk, and we rely on our colleagues for support and advocacy. We often face stereotypes that unleash our deepest insecurities which can lead to imposter syndrome. According to the Women in Cardiology Chapter of the American College of Cardiology (ACC), "There are more women in cardiology now than in the past, but women are only 18% of cardiology fellows, 10-15% of practicing cardiologists and 4% of interventional cardiologists". As one of 4%, I can attest that… I am different, I am unique, but I am not alone. I tell this story today not just as a voice of the 4% but also as a call to action to the 96% for their advocacy and support. Like the male ER attending who gave me the strength and confidence to push forward, so can so many others. Not a day goes by that I do not feel grateful for my profession and my colleagues at UCLA, yet I am keenly aware of those feelings of doubt, stress, lack of control, and being different. Sometimes they come from within, but sometimes they come from the voices around me. My friends, colleagues, patients, and family remind me every day why I continue coming to work – I hear their voices and they help me to face and overcome new challenges as best I can. And every time my pager goes off or I hear the sirens of the ambulance approach, my heart still beats a bit faster but also a bit stronger and more resilient… I have been here before and will be here again. I will do my best and hope that it is enough - for that is all we can ever do.

To view the recording of this story, which was presented at UCLA Department of Medicine Grand Rounds on January 11, 2024, please visit https://bit.ly/3UQoJcV

ON EQUITY STORY SLAM

"The Perfect Fit"

Amy L. Cummings, MD, PhD

I run clinical trials in lung cancer, which has the unique distinction of being the number one cause of cancer-related mortality in the United States and around the world. Lung cancer kills more people each year than the other top five cancers combined. Luckily, we have started to make some progress, largely as a result of clinical trials. However, still, if you have a lymph node in the middle of your chest, a mediastinal lymph node, only three to four people out of ten are going to survive five years. That's our surrogate for a potential cure. And it hasn't changed for the past thirty years. However, we have begun to launch clinical trials in earlier-stage lung cancer. And they are moving the needle. In the first one, CheckMate 861, we doubled the number of people that made it five years, which is tremendous progress.

I have one of these clinical trials open right now. You just know when you have a good one. The people you put on the trial do well, have few side effects, and thrive. Smiling faces in the clinic, grateful that they got a chance to really live. I get many calls from my colleagues about referrals and potential candidates. In September, I got one of these calls from Jay Lee, one of our thoracic surgeons. He said, "Amy, I have the perfect fit for this trial. This person is young and healthy, has a targetable mutation, and has mediastinal lymph node involvement. We have a chance to get this guy. There is just one thing: he has a managed Medi-Cal."

I've taken on insurance problems before. I can be creative and have gotten my way more than a few times. Even probably when I shouldn't have. Without hesitating, I replied, "No problem, Jay. Let my team work on it, and we'll see what we can do."

I received the first update twenty-four hours later: "We need an OTA and prior authorization."

"Thanks," I emailed back, "please proceed."

At the end of the week, I got my next update. "The original request was denied, but we can put in a letter of medical necessity that they can review within fifteen to thirty days."

At that time, I started to get nervous. For earlier-stage lung cancer, we like to get people treated within six weeks. We had to get this guy going.

"Can I do a cash-pay one? Let's bring him in for a hundred, sign consent, and move on?"

The reply: "Dr. Cummings, that is not in line with compliance. The entire institution could be audited and fined. You cannot do that because there cannot be any option cheaper than a managed Medi-Cal."

I threw up my hands. "Okay, all right. No to that then." Next time I wouldn't put that in writing.

Letter of medical necessity it was. Jay had to write it. And he did it the same day. We both believe in this trial. Both believe this person should get this chance. Time goes on, and fifteen days pass. We're still waiting. We get to the thirty days. We should have heard an update by now.

I reach out to the team and get the response: "The authorization timed out. We need to start again. We must return to the original primary care doctor and get them to re-up the OTA."

My stomach sinks. This is a person, who has a family, and a potential life-ending cancer. He and they have been waiting for days and days, and now it's been a month. Even if I got him in tomorrow, there would be no way to get him to trial within six weeks of diagnosis. And there was still no guarantee that we could get him in, even if we got the OTA again. We could do this dance all over and still end up in the same place. A negative by default.

"It's okay." I replied, shaking my head. "Tell him to proceed with in-network care." I archived the email, sending Jay a text, "I'm sorry, we couldn't make it work for that guy."

He replied quickly. "No problem, it was a heavy lift."

So, this is a story about someone I never met. Someone who I do not know and never will know. And while I wish this story was unique, it is not. It plays out every day all over California, one of the most fractured health systems with some of the lowest reimbursement rates, most comparable to those offered in Kentucky, for our safety-net plan that covers 15.5 million. There are literally millions of people who have had something like this happen. More people than I will ever know. I knew this gentleman needed to go onto the treatment he could get and take his chances. He still had a shot at a cure, albeit with slimmer odds than I would have liked. Slimmer odds than my patients have. But I couldn't have him hanging on for an option that was not real.

So, this is also a story with no end. I do not know if he got surgery. I do not know if he got chemotherapy. I do not know if he did well or is doing well, or is cured. And I also do not know if this trial would have made the difference. But I do know we have saved lives on this trial, and that it is going to be the new standard-of-care. I also know we are the only country in the world that runs clinical trials through insurance to save money for drug companies. So, I have decided to give up part of my salary to take on a position in our cancer center to work against exactly this, because I do not want someone who is the perfect fit not to have a chance.

To view the recording of this story, which was presented at UCLA Department of Medicine Grand Rounds on January 11, 2024, please visit https://bit.ly/4bD5OYu

ON EQUITY STORY SLAM

"A Tale of Two Patients"

Adrian Mayo, MD

In preparing for this talk I, like all the other speakers, thought long and hard about what to discuss. Do I discuss the infamous "where are you *really* from" question I still intermittently get asked? Or do I talk about how I have been privileged to at times pass for a tan Caucasian or how I am ethnically ambiguous enough to avoid racism (it's hard to hate someone if you can't tell what part of the world to discriminate against). Instead, I decided to share two patients I have had the pleasure of knowing.

These two patients, let's call them Lourey and Mary, have had many similarities in their paths.

Both Lourey and Mary had rough childhoods. They both came to this country when they were young, their parents seeking a better life, however, both learning quickly the arduous nature of survival required for "the American dream". They both had several forms of trauma during their childhood in addition to language barriers and socioeconomic barriers, effects which lead to persistent issues into adulthood. Having never learned constructive coping skills, they both found a similar way to deal with the unbearable suffering of being, finding some peace in prescription narcotics.

It is here where Lourey and Mary's paths start to diverge. Lourey, despite her addiction, managed to get a good job and move to a nice neighborhood, while Mary continued to struggle financially. Because the economics of opioid addiction led Mary to find her way to smoking heroin.

Although both women carried a similar diagnosis, their experiences continued to diverge. While both women would sometimes find their way to an ED with fake or possibly exaggerated depictions of pain requiring narcotics, Lourey's new status in life afforded her the luxury of continued access to quality care and to opiates. Mary, on the other hand, was given cold looks from nurses, dismissive doctors and even when she truly was in pain, was often ignored.

Both women did try to quit, both going to rehab at least 5 times over the span of 5 years. Eventually they were both able to remain sober for many years, Lourey still remains sober to this day.

However, eventually COVID came around and both women lost their jobs, had ugly divorces, struggled to pay bills and sank deep into depression, while also unable to find psychiatric care after the loss of their employer-based medical insurance.

It was around this time that Mary was eventually forced to leave her home and move to the streets. Now suddenly, people in hospitals as well as on the streets had a whole new reason to dismiss her; and they did, as she fell deeper into social isolation, addiction, and depression.

I had another patient mention how social isolation is one of the hardest parts of being homeless. Not feeling like a human, being required to defecate in public as the bathrooms get locked up, not having access to daily showers or laundry and the looks and the stares from housed individuals. But even the opposite can drive the knife of "you are different" deeper into one's gut. We all do it, that moment when you pass someone on the street corner and purposely avert your gaze from them, hoping that ignoring this human-shaped ball of flesh on the corner is more appealing than looking eye to eye with the failures of the US social safety net.

When I first met Mary on the street, we spoke for 40 minutes about various aspects of her life story. In the end, the only things I thought we gave her was some ibuprofen and information on how to establish with mental health services.

"You're the first doctor to treat us like human beings" she said. "Thank you for not treating me like I don't exist".

After we hugged, something she politely requested prior to leaving, I sat and pondered, shaken by her words. In the EDI world we talk a lot about privilege and the importance of knowing your own privilege. I never considered the privilege I had of being assumed to be a human, nor the privilege I'd get to make someone else feel human again. Makes you wonder what it really means to be a doctor or to care for someone. It seems like it goes far beyond ibuprofen and referrals.

Makes you wonder what it means to be a "bad patient" when one's experiences in healthcare have been marred by shame and judgment. When patients have to navigate a healthcare system that is often confusing even for us physicians steeped within it. How difficult is it to make it to an appointment when you have no phone for follow up reminders, when it's difficult to know even what day or time it is or what buses to take to get across town. When you have to worry about whether the only things you own in this world will be stolen if you leave for too long. When you're running on too little sleep because every night is a battle for your safety.

Fortunately for our other patient, Lourey, she was eventually able to keep her home, able to stay sober, eventually get a job and start returning to her life 2 years later.

I've spent time thinking about the differences between these two women. Why did one path take such a harsher turn? Yes, there was the initial better job and financial status but that mostly disappeared during Lourey's struggles during COVID. Was it sheer will power? Because both of these women were clearly strong independent women who managed to successfully survive for so long and raise children on their own who cared for them. They both suffered throughout their lives, struggled at times with addiction, and had extreme economic hardships during COVID.

No, the main difference that I see is the support they had at a crucial inflection point in their lives. Lourey was fortunate enough to have children that started to do well financially during COVID and were able to support her during one of her lowest lows. One of her sons worked here at UCLA.

You see, ultimately as much as we may or may not realize it, homelessness, hardships, having your humanity stripped from you, only takes a few timely placed horrible life events.

It could happen to anyone.

To view the recording of this story, which was presented at UCLA Department of Medicine Grand Rounds on January 11, 2024, please visit https://bit.ly/3yctSDb

ON EQUITY STORY SLAM

"The Watcher"

Evan Michael Shannon, MD, MPH

"The next patient on the list is a watcher," my colleague informed me during evening sign-out, in my second month of internship.

Even early in my training I was beginning to appreciate the gaps between what I thought I learned in medical school and real-world experience. As a student, I failed to grasp the depth of healthcare inequities in the US. Now a newly minted physician, I started seeing the differences between how people were treated based on their race, income, and health insurance. For example, our cardiovascular center, where I was currently sitting, is a gorgeous new facility, with glass facades, large private rooms, and views of one of the most expensive zip codes in the country. Our patient population was not reflective of the city as a whole. Our patients were mostly affluent, White, and referred from across the region if not the world. Meanwhile, across the street in the main hospital, which looked ominously like downtown LA's twin towers, our patients reflected the population of the surrounding neighborhoods: Black, Brown, from the resource-stripped areas of the city.

Michael was an exception to this usual rule. He was a young man of color, experiencing homelessness, and admitted with bacterial endocarditis involving his native tricuspid and surgically replaced aortic valve. Past injection drug use had led to a previous bout of endocarditis requiring surgical intervention a couple of years prior. Gentrification of his neighborhood, caused in part by an emerging class of educated young professionals like myself who could afford the skyrocketing costs of living, had priced him out of his home and rendered him homeless. Now, an interloping colony of staph aureus had rendered his tricuspid valve an impotent shorn sail while another sizeable and enlarging one was loosely adhered to a cusp of his porcine valve.

Early in my training, I began noticing biases in how people experiencing homelessness and those with a history of IVDU were discussed. That they are "challenging," "difficult," "easily agitated," "causing disturbances," and "non-adherent." I was already noticing that despite my rejections, these impressions were starting to seep deeper into my held implicit biases. I wondered how often these biases affected decision-making for mw and for other patients.

In Michael's case, while he had clear indications for surgical repair of his valve, there were no active plans to take him to the OR. The alleged reasoning: his previous sternotomy had been too recent and therefore repeat was too risky. I had to wonder if the subtext was, to put it bluntly: "We don't want to waste resources placing a new aortic valve in this homeless guy who uses injection drugs." The plan was to continue antibiotics and hope the vegetations would involute.

Attempting to repair his valve as "too risky" was a perplexing notion to me. As physicians, we constantly weigh risks and benefits of any medication we prescribe or procedure we perform. In Michael's case, the risk of not performing the repair was substantial: worsening heart failure, stroke, scattershot distal emboli to his organs and extremities and possibly death. Didn't the risk of not intervening outweigh the risk of doing so? Only recently, the Watchman, a small device placed into a patient's left atrial appendage, was approved by the FDA. Imagine being one of the first recipients, or deliverers, of this device? Across the street in our cancer center, severely ill patients were being injected with experimental therapies for the promise of a prolonged survival of a median of a few months. I wondered: Would the approach be different if Michael was stably housed? Or insured? Or if he was White?

Soon after sign-out, I received a page from Michael's nurse, saying he wanted to talk about the plan. I rolled my eyes, if not physically, internally, as I calculated how much time the interaction would compromise from my myriad of other tasks that evening. I met Michael in his bed, shirtless, emaciated, looking somewhat uncomfortable. "Hey doc," he said. I was disarmed by this cordial greeting as I anticipated that he would be "challenging" to interact with. Michael asked me about the plan for the following day – apparently there was a possibility of him being transferred to a community hospital that was willing to consider a repeat valve replacement. I told him I was unsure and that he could ask his team that knew him best first thing in the morning. As I responded, I felt a pang of guilt that our state-of-the-art cardiovascular facility was unwilling to take our patient to the OR, but was happy to ship him out to another hospital.

Several hours later, I was paged about Michael: "Patient's blood pressure 80s/50s, please come assess." I would have to draw Michael's blood using ultrasound guidance, as years of intravenous drug use had scarred his superficial veins. We continued to talk. He divulged details about his life: how challenging it was to find steady employment after incarceration, how he had a young daughter that he loved dearly, but could only rarely see in person. "I want to get better so I can be there

for her," he told me. After Michael's blood pressure stabilized with fluids, I was paged away to respond to another patient.

In the early morning, I was paged again about Michael. "Patient's SBP 70s, he's altered and short of breath, please come assess." He appeared paler than when I'd seen him earlier – he was restless and intermittently groaning. "What's going on, Michael?" "What? I don't know man. Where's my daughter? Can you call my daughter?" I knew this would not be possible – she was 6 and it was 3 in the morning. "I don't want to die man. I don't want to die," he said tearfully. I squeezed his hand. We were able to intubate him, start pressors, and get him to the ICU. But just hours later, he became pulseless. We initiated CPR. We continued the code until his sister, who lived nearby, was able to come to the bedside. Soon after, we stopped compressions.

That night with Michael has stayed with me now nearly a decade later. I think back on the biases that I held toward people experiencing homelessness and those who use intravenous drugs. I can't help but wonder if similar biases affected the decision-making of the surgical team. I also reflect on the ways in which society had failed Michael. If social determinants of heath are responsible for nearly half of health care outcomes, to what degree was Michael at fault for his condition?

"Who watches the watchmen?" As physicians, we carry great power and responsibilities for our patients. Many of our decisions are clouded by biases. Often, we are not made accountable for these flawed decisions. Except for the patients who were affected by them. Similarly, who is held to account for the policies and societal structures that have perpetuated such suffering among our most vulnerable patients? It is easy to feel overwhelmed by this notion and the work required to create a society that is truly just. But one can strive to acknowledge our biases and approach our patients with the dignity and respect that every person deserves at their time of need. Our patients are watching.

To view the recording of this story, which was presented at UCLA Department of Medicine Grand Rounds on January 11, 2024, please visit https://bit.ly/3WuqUnG

ON EQUITY STORY SLAM

"More Compassion, Less Judgement"

Soma Wali, MD, FACP

MJ, a 19-year-old woman, faced her third admission for a drug overdose. However, as the medical team began discussing her case, preconceived judgments overshadowed her struggles. Described as a difficult and unpleasant patient with drug-seeking behavior, her story unfolded with a surprising complexity.

Approaching her room, the weight of realization hit me that MJ was someone's daughter, the same age as my own, resonated deeply. Disregarding the team's biases, I introduced myself and empathetically conveyed my intention to help her overcome addiction. A gentle touch on her shoulder bridged the unspoken gap and offered immediate comfort.

Learning about her pain and withdrawal symptoms, I assured MJ of medication while expressing my goal to break the cycle of drug abuse. As we delved into her history, a painful narrative emerged. A victim of the foster care system, MJ endured emotional, physical, and sexual abuse from an early age.

Running away at 16, MJ found solace on the streets but was compelled to sell and use drugs to survive. Her resentment towards doctors for repeatedly saving her life underscored the deep despair she felt. The harsh reality of her homeless teenage years weighed heavily on my conscience.

After a night spent reflecting on MJ's plight, I resolved to make a difference. By taking the time to understand her, I could offer genuine support. This encounter challenged the stereotypes surrounding drug addiction and homelessness, highlighting the importance of recognizing the individual stories behind these struggles.

The story takes a positive turn as efforts to help MJ succeed unfold. With dedication, we assisted her recovery, addressing housing concerns with social workers. MJ's commitment to change manifested in securing a job and pursuing her GED. Her dream of becoming a nurse emerged, and the narrative concludes with MJ enrolled in a nursing program, radiating happiness and hope.

This experience serves as a poignant reminder to approach patients with compassion rather than judgment. MJ's story exemplifies the transformative impact of understanding, proving that taking the time to know our patients can lead to genuine healing and life-changing outcomes.

To view the recording of this story, which was presented at UCLA Department of Medicine Grand Rounds on January 11, 2024, please visit https://bit.ly/4b6SYC1

ON EQUITY STORY SLAM

"Long Weekends"

Sun Yoo, MD, MPH

Mr. A was one of the first patients I took care of in the Extensivist Program. Before meeting Mr. A, I reviewed his chart to see if I could glean details that would help me connect with him. He was in his 40s and had sickle cell disease. He also had end-stage renal disease requiring dialysis, cardiomyopathy, cirrhosis, and severe pulmonary hypertension. He had been in the ED over 50 times in the past year. I was uncomfortable with the number of times I saw "non-compliant" written across his chart. Non-compliant with dialysis. Non-compliant with medications. Non-compliant with medical care.

While I was reviewing his chart, I saw that he had just come to the ED. I saw this as an opportunity to meet him, as I am not sure he had ever made it to an outpatient appointment. After I finished clinic that morning, I went to meet him in the ED. He was lying in a hallway bed, with half the bedsheets hanging off his bed, surrounded by beeping IVs. I introduced myself and asked how he was doing. He had just received his pain medications, so he was doing a little better. Although guarded at first, he slowly warmed up as I continued visiting him in the hospital daily.

In the first few months I cared for him, I went through his chart and replaced "non-compliant" with the reasons he had difficulty with medications, dialysis, and his care plans. None of his care plans reflected the daily struggles he faced driving over an hour to get to dialysis while in pain, having side effects from his medications, picking up pain medications without being made to feel like a criminal, or sometimes being in so much pain he could not get out of bed. I spoke with his multiple specialists to get their input on what we could do to decrease the number of pain crises. His nephrologist made changes to his dialysis regimen. His hematologist restarted his medications at a reduced frequency. We arranged outpatient transfusions and he came to my clinic for pain control. We always checked in before long holiday weekends as we knew how hard it was to get anything done on those weekends. He also sent us an email on those weekends to tell us everything was going OK in his world, as he was worried we would be worrying.

Over the next two years, he spent less time in the hospital. He was hospitalized about once every 2 months rather than once a week. When he went in, he would call me or my care coordinator so we could facilitate the admission and visit him in the hospital. As he spent more time at home, he started socializing more. He was excited to attend a restaurant opening with his friends. He invited me and our team to a barbeque. He came for our weekly visits, sometimes they would be for pain control, and other times, for a social check in.

Despite all our efforts, his health inevitably got worse. He developed heart failure, sepsis, and eventually multi-organ failure. I think we all forgot how sick he was, how sick he had been for a very long time. Through a lifetime of suffering, he developed a tough exterior baked in resilience. At this moment I realized I had not done a good job with advance care planning. We spent time exploring his values, his hopes which included spending time outside the hospital and getting a transplant, his fears, and his treatment options. We did not talk about how his disease could and would get worse and he could become sick really fast. I felt like I had failed him at this time. He trusted me and I was in the perfect position to have these conversations with him when he was doing better. We know based on the literature that structurally marginalized groups have lower rates of advance care planning. I should have better prepared the patient and his mom for what was to come. I vowed to do better.

On his final hospital admission, we confirmed there were no other advanced therapies available for him, and he was discharged home from the hospital, based on his wishes. He thanked our team for caring about him as a person and always being there for him. He said he always felt comfortable coming to our clinic, and he felt seen and heard.

He ended up passing away at home over the long weekend, and it proved to be a cold winter for all of us who cared for him. Whenever we have long weekends, I still remember the emails he used to send us and am reminded by the extreme privilege we have as physicians to take care of patients in the toughest moments of their lives. It also reminds me of our duty to have the tough conversations with our patients, especially those that are seriously ill, so they can make informed decisions about their medical care.

To view the recording of this story, which was presented at UCLA Department of Medicine Grand Rounds on January 11, 2024, please visit https://bit.ly/4dwtjEc