

Introduction: We are pleased to present the second in our series entitled “On Equity Story Slam”. The following seven essays were presented at the Department of Medicine Grand Rounds on January 12, 2022. The presentations were organized and coordinated by the Committee on Equity, Diversity and Inclusion, led by Keith Norris, MD, PhD, Distinguished Professor of Medicine and Vice Chair for Equity, Diversity and Inclusion, Christina Harris, MD, Health Science Associate Professor of Medicine and Cristina Punzalan, Administrative Director.

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 12, 2022 is included at the end of each submission.

ON EQUITY STORY SLAM

“Getting Personal”

Gregory A. Brent, MD

I donned the mask, gown, and gloves to enter Peter’s room, with some trepidation. I was perspiring from the restrictive gear, had trouble breathing, and had growing concerns that I did not know what to do. Peter was in his late 20s, in good health a few months ago, but now was gasping for breath with maximal supplemental oxygen. We were both anxious. I told Peter that we were treating an infectious agent that we had identified in his sputum and was causing his pneumonia. Inside, though, I was not at all confident that he would respond to this treatment.

This was not a patient with COVID pneumonia in 2021, but 40 years earlier, in 1981. Back-to-back articles had been published in the *New England Journal of Medicine*, describing a series of patients from Los Angeles and New York, young previously healthy gay men and individuals using intravenous drugs, with pneumocystis pneumonia, mucosal candidiasis, some with Kaposi’s sarcoma, and an acquired cellular immunodeficiency. As an intern, I had read of this newly described immunodeficiency with academic fascination and had discussed it in case conferences with my colleagues and attendings, but now, as I looked into Peter’s frightened eyes...it was personal.

Peter was the first of many patients I would care for during my residency with what was called AIDS, and we now call HIV. I was uncomfortable on many levels. Peter was about my age and he had a disease that many were dying from despite our best efforts. We were on the frontlines of a killer, that seemed to require sexual contact or exposure to blood products for transmission, but we did not know. I feared for my own exposure, a fingerstick from an IV or blood draw, bringing it into my home and exposing my wife.

I had treatment to offer Peter for the pneumonia and candidiasis, but not the underlying immunodeficiency. I was uncomfortable asking for detailed information about sexual practices and partners. Peter looked past my fear and discomfort and correctly read my desire to connect with him. I am not now advocating

that you ignore sound infection control policy, but that is what I did. I discarded the gloves, sat on Peter’s bed, and held his hand as I spoke to him, making a physical connection that made both of us feel better.

Peter taught me that being at the end of my ability to provide a curative intervention was just the beginning of my ability to provide comfort, hope, and emotional healing. This first experience with Peter on the VA wards, the connection we made, helped me with the many patients I cared for throughout my residency, as I rotated through UCLA CHS and in the pulmonary ICU at Cedars-Sinai. The names and stories changed, and it was never easy, but I sat at the bedside and held the hand of many young gay men as we navigated this unimaginable epidemic together... it was becoming more personal.

As our treatments improved, some patients recovered to return home, but many did not. I can point out to you the rooms on the wards and ICU where young HIV patients died. It still brings up feelings of helplessness and sadness in me, and even tears, as some of you will experience in the future as you recall and describe your time caring for COVID-19 patients. I sat with grieving families, mourning the senseless suffering and loss of their loved ones. But in many more patients than I expected, including Peter, there was no family present. Many of these individuals had been rejected by their families. In some cases, just by virtue of being gay, in others, out of fear of contracting AIDS. A common narrative from many corners, religious and secular, was that AIDS was a deserved consequence of immoral behavior, a judgement from God, a further reason to shame and marginalize an already vulnerable population.

I wish that I could confidently tell you how far we have come in 40 years in our care of LGBTQ individuals, but I can’t. Twenty years ago, I became involved in a healthcare alliance for transgender patients at the VA, not from any great

knowledge or experience at that time, but because only a handful of providers were willing to care for these individuals. Although much progress has been made, especially in transgender care, LGBTQ individuals remain marginalized in our health care system. They experience health disparities in many areas, including mental health, cancer diagnosis and treatment, and reproductive health. They regularly experience implicit and explicit biases when seeking care. We make assumptions about our patient's sexual orientation and gender identity that reflect these biases in our greetings, the use of pronouns, the questions we ask, and our selection of tests and treatments.

I want to be an ally and advocate for the LGBTQ community and be bolder. I am so appreciative of the patients, trainees, and

colleagues who have graciously helped me identify my own biases, guided me, in practical ways, to create and promote an affirming manner and environment. I hope that you too will be challenged to be an advocate for inclusion. The LGBTQ community is made up of unique individuals, each with worth and value, and deserve our respect. I believe that they each reflect God's image, not his judgement. They are my neighbors, my students and trainees, my colleagues, several members of my extended family, and most significant to me, my son.... it is very personal.

To view the recording of this story, which was presented at UCLA Department of Medicine Grand Rounds on January 12, 2022, please visit <https://bit.ly/dr Brent story>.

ON EQUITY STORY SLAM

“Allowance”

Judith S. Currier, MD

It was the weekend before Thanksgiving in 2020, just at the beginning of the second COVID surge in Los Angeles. I was working on an outpatient clinical trial designed to test whether plasma obtained from people who had recovered from COVID, with high titers of neutralizing antibodies to COVID-19, would prevent progression of disease and hospitalization in people who presented within eight days of the onset of symptoms. Hopeful that this treatment could really make a meaningful impact, the study team had a recruitment strategy including a variety of methods, printed ads, internet posting, outreach to providers, and word of mouth. A national outreach program also included radio ads in English and Spanish and TV spots and a website. But despite these efforts, recruitment was slow, even with the surging number of cases. The public messages were to stay home if you had COVID and we were trying to get people to come to UCLA to receive an experimental treatment. It was a heavy lift.

I received a call that we had a potential study participant and that she also had several family members who had recently been diagnosed with COVID. The matriarch of the family, Mrs. M, had been referred by her employer to our study coordinator. Mrs. M and her husband arrived at our study site. The COVID pods were situated adjacent to the Clinical Translational Research Center at UCLA in parking lot 27. I gowned and masked up and met them inside the pod, a small trailer converted into an exam room, to review the trial and the informed consent. Mrs. M was a Hispanic woman in her mid-60's with obesity, a history of hypertension, hyperlipidemia, and diabetes. She had developed a fever and cough two days prior. Her employer, a medical professional, helped her get tested and when the result came back, referred her to UCLA based on an ad she had seen.

During our discussion, I learned that this family of six had all been diagnosed with COVID over the past few days. A recent fire in one of their homes had forced them all to congregate together in a small apartment. Mrs. M was clearly at high risk for progression of COVID. She was coughing intermittently as we talked, but was not short of breath. We sat together in the pod, and I explained the study in detail, reviewing the risks and benefits, alternatives, and the study visit schedule. I explained what the study provided and what her participation would entail. She listened intently, as one would when motivated by the fear of being hospitalized or even worse, dying. This was November of 2020, we had no approved treatments for COVID and no vaccines. When I asked her if she had any concerns about participating in a research study, she did not follow up

with the questions that typically follow, “What about side effects or recovery time?” Instead, her only concern was whether she was allowed to come to UCLA to be in the study. At first, I was not sure what she meant. My reaction was, “Of course you are allowed to come to UCLA. Our studies are open to everyone, why would you not be ‘allowed’?” She explained that since she could not come to UCLA for her primary care, because of her insurance, she just wasn't sure she could be in a study here either.

Mrs. M's fear of “not being allowed” to be at UCLA has remained at the forefront of my thoughts over the last year. It has influenced how I think about the outreach program for our clinical research trials and the ways we try to get the word out about our trials. We did not reach Mrs. M through our outreach, we reached her employer. Mrs. M's story comes to mind when the ID faculty come to me, frustrated after caring for a patient on the inpatient service for weeks, finally making inroads on a complex or refractory infection, only to be denied the opportunity to see the individual in follow-up due to their insurance status.

Mrs. M's feeling of “not being allowed” is a powerful one that has a far-reaching impact on both the research and clinical missions of UCLA Health. If our vision is to “heal humankind, one patient at a time, by improving health, alleviating suffering, and delivering acts of kindness,” we must address the barriers that stand between UCLA Health and the people that make up the many communities of Los Angeles. COVID has heightened the incredible health disparities surrounding us. There is no better or more important time to act.

Mrs. M and five of her family members enrolled in the trial. The trial results demonstrated that the early use of high titer convalescent plasma reduced the risk of hospitalization by 54 percent and these results may alter the availability of this treatment for early disease in the days ahead. I think Mrs. M found the experience of participating in research to be beneficial and clearly her participation benefited the trial finding a result. But this experience was especially important for me, as it made me think about the ways in which we can move from making people feel “allowed” to be at UCLA, to welcoming them to UCLA as equal and valued members of our community.

To view the recording of this story, which was presented at UCLA Department of Medicine Grand Rounds on January 12, 2022, please visit <https://bit.ly/drcurrierstory>.

ON EQUITY STORY SLAM

“May God Bless Our Hands”

Alina Kung, MD, MS

The truth is, I don't know much about Mr. J. This happens sometimes when you receive a patient in the ICU. They arrive, intubated, sedated. And over the course of their stay, you may never hear their voice. You instead become familiar with the rhythm of their breath, the cyclic ins and outs of their body, their chemistries coming in and out of balance.

I do remember Mr. J's skin, pale, slightly damp as he continued to fever, oily as he approached his second week in the ICU with COVID pneumonia. I remember his dark curly hair. I remember the curve of his right ear as I did as I was implored, to say out loud to his sedated body, "Mr. J, your wife and children want you to know that they love you very much and want you to get better."

I remember his wife's voice, in variations - a sob as she learned that her husband wasn't getting better, a cry as she wrestled with the implications of him being DNR/DNI, a wail after we told her he had died. And then, suddenly made real, she was there - outside his room, shortly after his death, looking in. His skin was paler yet, his body unnaturally still.

I slowly walked to her side. She spoke. "I was hoping, because he was young, that he would have a chance," she said. She shared how they had four children together. That her daughter had tested positive for COVID too. And then she said, "May God bless your hands," and gestured to the other ICU patients behind their sliding glass doors. "So you can save the others." I placed a hand on her back and she leaned her head against my shoulder. We cried together. Then we let go.

After she left, I washed my hands and let my tears fall freely at the sink. An ICU nurse saw me, and I remember my surprise as she gave me the first hug I had in weeks. "I want you to remember this moment," she said, crying herself. "When you talk with families, you have to set expectations. All of them. You have to tell them they are terminal." And I realized in that moment, we were swimming, maybe drowning, in a deep despair together. We had watched the same story unfold over and over - refractory hypoxia, acidemia, attempts at resuscitation, calling the time of death. I drove home, and listened to some music. I cried again in my friend's lap. I lit incense in remembrance of Mr. J., and watched the smoke dissipate, and the stick turn into ash. Very slowly, I moved on.

But despite this happening a year ago during the winter surge, the ICU nurse's statement lingers with me. "You have to set expectations," she said. Those days at our safety net hospital we

were boarding over 100 patients on the wards and ICU with acute hypoxic respiratory failure from COVID. We would watch our patients die from acidemia, and wonder if we could've given their families more time had we had more nurses or dialysis machines. The admissions felt relentless, and in those weeks, we almost exclusively freed ICU beds by our patients dying. A large refrigerated truck was parked in the parking lot to hold the bodies because the morgue was full. Mr. J's wife had blessed our hands, but I knew here—in this under-resourced hospital and underserved community, they were tied.

I know from having my primary care clinic here that I could fill in more parts of the story. Poverty, stress, and lack of access to affordable and nutritious foods manifested as higher BMI's and uncontrolled diabetes. People worked in jobs without formal protections or adequate access to PPE, and lived in homes where they could not isolate from others. Decades of not knowing which public services to trust possibly resulted in more delayed and severe presentations. These themes culminated in our ICU where we tried to give our patients the best of the narrow chance they had.

Had Mr. J lived in a more affluent neighborhood or presented to the ICU of our academic hospital, where our resources are more abundant, would hope be more available? Our sense of possibility more open? Here, would we ever reach a nadir of despair and say out loud, "You have to set expectations. You have to tell the families - all of them - our patients are terminal."?

Her statement was one I only heard once, and expressed in the darkest of moments. However, it illustrates one of my greatest fears - that we become part of perpetuating disparate outcomes when we accept them as normal. When the system fails us, we lower our expectations. We normalize dysfunction, scarcity, stratification. And I understand how that form of coping is important and protective. If we had let ourselves remember the truth - that every system is perfectly designed to deliver the outcomes it does - we would be overwhelmed. We would be heartbroken at the harm that happened on our watch, angry at the injustice, and frustrated at the lack of a clear target for accountability.

But human hands built this unequal system. And just as Mr. J's wife, who had just experienced incredible loss, still found a place to bless our work, we too can traverse our heartbreak, our anger, our frustration. Our hands may be tied in some settings, but we can be curious about the knots that bind them. We should

wonder why we have chronically underfunded and overwhelmed our county health facilities. We should wonder why hope is a privilege. We should wonder why more of our immigrant, our poor, our communities of color are dying of the same virus. We should wonder if we're doing our part.

I'll likely remember this part of my training for the rest of my life. I'll remember the ICU nurse's statement and Mr. J. I'll also remember the hands that comforted my crying, and my primary care patients coming back to see me after losing their own family members to COVID. I'll remember the progress we've made in more justly allocating novel outpatient COVID thera-

pies, and the opportunity we have in waking up society to the brokenness of our system – a brokenness of the system, but not of ourselves. I'll remember the way forward is simple – to keep our eyes open to injustice, to care, and to act from compassion.

If we loosen these knots that bind us, perhaps we can free each other. May God bless our hands. So we can save the others.

To view the recording of this story, which was presented at UCLA Department of Medicine Grand Rounds on January 12, 2022, please visit <https://bit.ly/drkungstory>.

ON EQUITY STORY SLAM

"We Don't Use the 'A' Word"

Alice A. Kuo, MD, PhD

During one of my busy Friday afternoon clinics in Redondo Beach last month, I hastened to room nine and gave a soft knock before pushing the door open. A woman quickly rushed to the door and pushed me out into the hall saying, "Doctor, could I have a word with you before you come in?" I nodded, and she went on to say, "So we don't use the 'A-word' in front of Tommy, and nothing referring to the spectrum. Okay?" Before I could respond, she opened the door and went in.

I entered the room and encountered a cute four-year-old perched on the exam table, looking at me quizzically. "Hi, Doctor. What's your favorite holiday?" Without waiting for my answer, he continued, "Mine is Halloween. I love monsters and zombies. Do you like scary movies?" "Not really," I smiled. Tommy went on to tell me in excruciating detail how zombies differed from monsters. He then asked me to find images of Knott's Scary Farm online, which he watched while I talked to his mother.

I'm an autism researcher. I apply a public health lens to a neurodevelopmental condition that is considered a psychiatric "disorder." I have also been the primary care provider for over 400 autistic patients of all ages—as young as infants and as old as seniors. As I've cared for all of these patients, I've thought about and embraced the notion of neurodiversity. That neurological differences like autism and ADHD are the result of normal, natural, variation in the human genome. We need neurodiversity like the planet needs biodiversity. It's necessary for survival or at least innovation. Without autism, we might not have smartphones, social media, or self-driving cars.

Last month, the CDC released data that autism prevalence is now one in 44 children, or 2.3 percent of all children, making it more common than red hair or blue eyes. And autism is not fatal, meaning that nearly 100,000 autistic children turn 18 and enter adulthood each year. I must say, though, that in the last couple of years I've had a few patients who actually celebrated their autism.

At the beginning of the pandemic, a colleague referred a family to see me. Ariel was an opinionated 12-year-old, who loved animals but struggled with social relationships and middle school. Her grades started dropping in seventh grade, after some significant bullying. And her parents were wondering about the possibility of ADHD. After a few meetings, I diagnosed not only ADHD but autism and anxiety as well.

The parents wanted me to explain autism to Ariel, so I did. The following week, I got a distressed email from her father that Ariel had made Tik Tok videos celebrating being autistic. I thought it was pretty cool, and asked her dad if Ariel didn't have a problem with being autistic, why did he?

I feel more confident about helping autistic children get to adulthood, but I am less rosy about outcomes for autistic adults. Autistic adults have an average lifespan of about 48 years. This shortened lifespan can be attributed to untreated cardiovascular disease, later diagnosed cancers, and unintentional injuries. To me, the common denominator is a lack of good primary care in adulthood. Research shows that autistic adults experience disparities in health services due to their autistic identity. Autistic individuals and their families report significant difficulty finding adult primary care providers willing or able to take care of them.

A few weeks ago, a 30-year-old autistic man named Jim, came to see me for pre-conception counseling. It was the first time that I had a male patient see me for this. He and his girlfriend of eight years had recently gotten married, and were thinking about having children. Both were physics professors at a local community college. Jim said that his father was probably autistic, he and his two brothers were autistic, and he also had several autistic cousins. So not surprisingly, he was wondering what the likelihood would be that his children might also be autistic. I told him that while 15 to 25 percent of autism could be associated with a genetic finding, we still didn't understand a lot about autism heritability.

I asked him how he was as a child. Jim described himself as always having trouble connecting with people. He had difficulty making eye contact and was bullied and teased about it throughout elementary school. He had trouble reading people's expressions, and once tore up a birthday card from a friend because he was convinced that she was making fun of him.

In middle school, Jim played water polo and one of his teammates took him under his wing socially. In high school, his tribe was a group of kids in honors classes where another peer also took him in, so to speak. In college, his social group was the physics club where he met his future wife. He got his Ph.D. in physics from UCLA and then got the teaching job where he's been for the last couple of years.

I gently reflected back to Jim that by all definitions, he was a successful adult with a loving wife and a steady job. “So what are you worried about?”, I asked him. “I’m not sure,” he said. “I just heard how hard it is to raise autistic kids.” “Raising any child can be challenging,” I replied. “Autistic or not. What matters most is that you and your wife will be there to support your children with whatever needs they may have. That’s what it means to be parents.”

So let’s turn back to Tommy. The first patient I told you about. The four-year-old who loves Halloween. His mom asked me whether he needed to go to a special preschool. And I said, “He knows the alphabet, can count to 20, and knows how to spell his name. I don’t see why he would need to go to a special preschool.” She then asked about ABA or behavioral therapy. “Someone told me I need to get 25 hours a week of ABA for him because of his, you know, condition,” looking at me with a knowing eye. “Well,” I said, “he sat here pretty cooperatively for the last half hour. Do you have any behavioral problems with him at home?”

“No, not all,” she said. “So why would you need ABA?” I asked. “What about his obsession with Halloween and horror

movies? What should I do about that?” “I don’t think you need to do anything about it at all,” I said. “Except maybe teach him not to get too graphic with his peers because you might have some parents calling you to complain.”

His mom then said, “What you’ve said during this visit is exactly the opposite of everything that everyone else has been telling me. When I think of all the doctors we met, you understand him the best.” I smiled and asked, “So then why are you afraid to use the ‘A-word’ in front of him?” Mom responded, “Well, you know, the world isn’t going to be kind to people like him. I’m worried he won’t fit in.” To that, I looked over at Tommy with admiration at his fearlessness of monsters and zombies, and said to Mom, “Why worry about him fitting in when he was clearly born to stand out?”

To view the recording of this story, which was presented at UCLA Department of Medicine Grand Rounds on January 12, 2022, please visit <https://bit.ly/drkuostory>.

ON EQUITY STORY SLAM

“Hidden in Plain Sight”

Tannaz Moin, MD, MBA, MSHS

Mr. P was in his early 40s when I met him the day he was being discharged from UCLA. His diabetic ketoacidosis (DKA) management had been relatively straightforward because he had no signs of infectious, cardiac, or other worrisome triggers. He was smoothly transitioned off his insulin drip to a basal bolus regimen and the Medicine team felt he was ready for discharge. But they asked us, in Endocrine, to see him before he left.

Although everything about his history screamed type 1 diabetes, like his slender figure and the fact that he had been insulin dependent since being diagnosed with diabetes in his early 30s, Mr. P told me he wasn't sure what type of diabetes he had. He'd been having a harder time in life these days, which made it difficult to take his insulin regularly. I remember thinking it didn't feel right discharging him so quickly that day, but there were so many consults to see, so I gave him my card and asked the team to make an appointment for him in our clinic, not sure he would show up.

But to diabetes clinic he came! And he did so for several weeks in a row. I was so relieved to see him again. It was in those weekly clinic visits that I got to know the real Mr. P. Eventually he told me he was living on the UCLA campus. Not in any of our housing facilities, but that he had found a variety of safe places all over the campus, most recently the sculpture garden, to camp out in the evenings. He said it was much safer than other places he had spent the night, so he liked it here.

Each time he would come to see me in diabetes clinic, Mr. P would bring his bright red and white cooler to fill up with cold drinking water. The nurses gave him bars and crackers we kept on hand if he was hungry, and we would talk. He had a kind smile and a friendly personality. He always greeted everyone warmly, and by this time, I knew our nurses had also taken a liking to his regular visits. He was really a pleasure to take care of and so appreciative of the care he was receiving!

I don't remember how times Mr. P came to clinic, but I was grateful we had found some time together. The time he deserved as a patient struggling with type 1 diabetes and the time he deserved as a human being who was struggling with life challenges.

But some of the clinic staff began asking questions, and the number of questions were increasing every week. Why was Mr. P, a homeless patient with no insurance, coming weekly to our

diabetes clinic? What would the other patients think? Uninsured patients need to go to county, period. And so, as it was directly explained to me, it was no longer *possible* for us to continue seeing Mr. P in our clinic. The nurses were worried they could get into trouble for letting Mr. P come back to clinic, so together we came up with an alternative. Every week, the nurses helped me leave clinic for a bit, taking some supplies to meet Mr. P near the Starbucks in Westwood Village. Each time we met Mr. P would thank me. We would talk about how things were going and plan our next meeting date and time.

And then one week, Mr. P didn't show up for our Starbucks meeting. I went back a few days in a row worried I may have gotten the days mixed up, but I never saw Mr. P again.

Over the last 10 years, I've thought a lot about Mr. P. I think of him at times when I walk around the UCLA campus. I think of him when I visit the sculpture garden with my children. I think of him when I go to Starbucks. Always wondering what may have happened to him. Always wondering what if....

What if I had insisted that we continue to see Mr. P in our clinic despite his lack of insurance?

What if we had the tools at our disposal to actually address his greatest needs? To do something about his lack of housing, or his lack of regular access to food and drinking water, or a safe place to store his insulin and diabetes supplies? What if we worked in systems that helped us provide not just the best care, but the best care for those with the most needs?

I will never know what happened to Mr. P, but what I do know, is that he embodies so much of what is broken in our healthcare system as a whole. Mr. P was a son, a brother, and an uncle who was facing life challenges, and he was deserving of the best care we had to offer for his type 1 diabetes.

But Mr. P was hidden in plain sight. He was hidden in plain sight on the UCLA campus where he camped out at nights, and where people walked by and barely noticed him. And eventually, he was hidden from our care altogether...even though there was so much more we could have done if only we had all just opened our eyes to see.

To view the recording of this story, which was presented at UCLA Department of Medicine Grand Rounds on January 12, 2022, please visit <https://bit.ly/drmoinstory>.

ON EQUITY STORY SLAM

“When Autonomy Means Failure”

Faysal Saab, MD

It happened during my intern year. Here’s the story, as written in my journal 10 years ago.

I had a shocking experience over the past 24 hours. Yesterday, while on call in the UCLA CCU, I was called to admit a 44-year-old man, let’s call him Mr. White, who appeared to be having a myocardial infarction. We urgently evaluated him in the ED and immediately sent him up for cardiac catheterization. The procedure revealed that his chest pain was actually due to coronary vasospasm induced from his recent cocaine use, but it was severe enough to have cut off vital myocardial circulation. He recovered well with the appropriate interventions and medications.

During my rounds the next morning, I counseled him that his cocaine use could have cost him his life and that he came very close to the brink. I asked if he also smoked cigarettes -- he told me he hasn’t in years and that he knew it was bad for his heart and lungs. I learned that he would sometimes stay at a place called Hotel Brooks, an old, precarious, and run-down institution I remember seeing a couple of blocks away from my apartment. I also learned that he was a veteran, and that he was 100% service-connected, meaning he was able to access most of the support services the VA has to offer. We gave him a sweatshirt and some bus tokens and he agreed to go to the VA the next day to seek more long-term housing services. I told him that today was a brand new day for him and he should use it as a time to start over since he came so close. I told him that cigarettes, cocaine, and alcohol should be avoided if he wants to live a healthier life. He told me he heard me loud and clear, and we discharged him.

Later that night I was driving to pick up my usual intern year Subway sandwich dinner when I looked out my side window and saw a few men standing on a dark street corner next to the adjacent 7/11. I looked closer. One of the men was Mr. White. He was still wearing his hospital pants, socks, and identification bracelet. I looked even closer. He was *smoking a cigarette*. I parked my car in the lot and just sat there. I was speechless and just stared out the window gazing at him. The first emotion I felt was shock. I thought, how could this man have come so close to death, thank us so genuinely for saving his life, only to smoke just a few hours later? I couldn’t believe that an individual with any hint of common sense could revert to their bad habits so quickly – in weeks or months, maybe, but *hours*?

My shock soon turned to frustration, which then turned into anger. I was angry that the healthcare system spent likely over

\$20,000 to help this man only to have him step all over it just a few hours later. I was angry that I apparently wasted half my day taking care of this man while I ignored my other sick patients who really did want to live. I thought to myself, why do I care about another man’s life if he doesn’t care about his own? I was frozen in that car, not knowing what to do. I wanted to talk to him, but didn’t know what to say. He was with his friends, and I wondered if it was wise to approach him by myself at night. I didn’t have a plan.

I finally walked up to him and said, “Mr. White what’s going on?” He said, “Oh hey there doc, I’m alright.” I said, “What are you doing, you’re smoking, after what just happened to you, I thought you told me you didn’t smoke?” He replied back “Aw man, I gave in, I just gave in.” He looked somewhat embarrassed and disappointed in himself. Then I switched to talking about other things for a while to avoid sounding like I was disciplining or admonishing him in front of his friends.

But I just wasn’t done with the smoking conversation – while he had denied it earlier that day, he couldn’t deny it now, so it was an opportunity to talk with him more about it. I asked him if the craving was just too much, and he said yes. I asked him if he’s ever tried to quit and he said yes. I asked him if he had ever used the help of a nicotine patch or gum or other medication to help him quit and he said no. I again told him that the cocaine almost killed him and that these cigarettes will do the same over time. He nodded in agreement, appearing a bit surprised that I was happily having this conversation in front of his 3 other friends, who were standing there, puzzled at this sight.

I told him that if he didn’t have people around him who cared about his life, that his doctors still cared, that I cared. That we wanted him to live a long life and it was too soon for him to go. And that if he’s already smoking soon after his discharge, I worry that he’ll start using cocaine again and die from an even bigger heart attack. I implored him to go see his doctor at the VA tomorrow to get help quitting. He looked in the distance and nodded. I thought to myself, he probably won’t. We said our goodbyes and I walked toward the Subway, ordered my sandwich, and headed home, *absolutely deflated*.

Today, in my 6th year as a hospitalist, I remember feeling that I had done a fantastic job counseling this man and had potentially changed the course of his life. But I think that’s rarely the case. We only get a glimpse of our patients when we meet them in the hospital – we often have no idea what’s *really* going on behind the scenes.

As an attending, I continue to cringe each time I discharge a patient to the street after they decline the housing and rehab services we offer. I think to myself, *what on earth* are we doing here? This is *absolute madness*, sending someone back to the same environment that got them sick in the first place. I think to myself, based on our current policies and standards of care, they have the capacity to make that decision. But isn't addiction a state of mental impairment that can affect capacity?

Autonomy is one thing when someone has a home, finances, a social support network, a PCP – in that situation they're more able to judiciously map out their decisions, and as their physician I'm comfortable with the principle that they have autonomy in their decision making. But I often wonder whether we can equally apply that principle to someone whose life is hanging by a thread – unhoused, financially insecure, poor social support network, and with substance dependence. Of course, that individual still has the *right* to make their own decisions, but is autonomy truly the paramount value here? There's an eerie sense of finality to letting someone with

substance dependence go back to the street without support – eventually, whether due to drugs, or violence, or lack of medical care, they'll have a poor outcome – we've seen it time and time again.

I have no idea what happened to Mr. White. I do know it is likely he may not be with us anymore. Looking back, what he needed was multi-level support – financial aid, drug rehab, stable housing, a PCP, and good friends or family at his bedside helping him make the right decision. Without any of those things, a healthy life would be difficult to attain. I'm not naïve, and while a tiny part of me hopes that a young doctor's genuine street corner concern reminded this man that a better life *is* possible, I fear that our unkind world and inequitable system had other plans.

To view the recording of this story, which was presented at UCLA Department of Medicine Grand Rounds on January 12, 2022, please visit <https://bit.ly/drsaabstory>.

ON EQUITY STORY SLAM

“Stay-at-Home Order”

Donna L. Washington, MD, MPH, FACP

My story is from a patient encounter in late March 2020, with one of my primary care patients at VA Greater Los Angeles Healthcare System. It was a momentous period of time. Two weeks earlier, on March 11th, 2020, the World Health Organization declared that the rapidly spreading outbreak of COVID-19 should be characterized as a pandemic.¹ One week earlier, on March 19th, 2020, California became the 1st U.S. state to issue a statewide stay-at-home order. The order mandated that the 40 million residents of California stay home or at their place of residence, except as needed to maintain continuity of operations of the federal critical infrastructure sectors or of other essential sectors.² The order also instructed health care systems to prioritize services to those who are the sickest.

In late March 2020, we did not have a lot of experience with the coronavirus. We also had not prioritized or triaged care on such a massive scale, so we were learning as we delivered and adapted our care. I and other primary care providers at VA Greater Los Angeles Healthcare System were encouraged to call our sickest patients, and determine how they were doing during this stay-at-home period. At that time, dealing with a pandemic was new to me. I did not have a script for these calls. I did not know exactly what I was looking for but figured I would recognize it when I found it. Fortunately, I had some tools to facilitate the process. I opened my VA electronic patient dashboard and sorted my patient list by Care Assessment Need (CAN) score. The CAN score is a validated estimator of the probability of hospital admission or death within a specified time period.³ It's expressed as a percentile, ranging from 0 (which is the lowest risk) to 99 (which is the highest risk). It indicates how a given Veteran compares with other individuals in terms of likelihood of hospitalization or death. My plan was to start at the 99th percentile and work my way backward.

It was sobering to see the names at the top of the list. These were patients I knew well, but for whom I had not explicitly conceptualized their likelihood of death within one year as a percentile. There were several elderly patients on the list. However, while still working through the percentiles in the 90's, I got to Ms. A's name. She was only age 50-something, but her medical problem list read like a “who's who” of the comorbidities, we would later come to learn conferred increased risk for severe outcomes with COVID-19 infection. She had diagnosed diabetes, hypertension, chronic kidney disease, chronic lung disease, and was currently undergoing chemotherapy for recently diagnosed breast cancer. I called Ms. A to ask how she was faring, and if she had difficulty staying home and having her needs met.

It turns out that despite the Stay-at-Home mandate, Ms. A was leaving her apartment daily. She was not an essential worker, in fact, she was not working at all due to medical disability. However, she was leaving her apartment daily because she did not have a working refrigerator. Ms. A had a cooler for her food and had to go out daily for ice. She also stored some food in the refrigerator of a family member, so made frequent trips there as well. As I probed further, I found out that Ms. A had a brief recent stint with homelessness. Though she was able to get an apartment just before the start of the pandemic, she was on a waiting list to obtain some of the furnishings she lacked and was still awaiting a refrigerator.

After being momentarily appalled by her plight, I quickly started calling around for a solution. I contacted the clinic social worker, who identified a social worker with the homelessness program, who was able to make some other calls and arrange for a refrigerator delivery that week. Thankfully, close to 2 years later, Ms. A has completed her chemotherapy and remains housed and COVID free.

So, what did I learn from this encounter with Ms. A?

First – I would agree that she was in the 90th percentile for hospitalization and mortality risk, but I would argue that in the midst of a pandemic, it was her social risk factors, rather than her medical risk factors alone, that placed her at the greatest risk. In fact, some of her social risk is mediated through the increased likelihood of having the chronic conditions that she had. Pandemics, similar to natural disasters and other crises, disproportionately disadvantage those who are already the most socially and medically vulnerable in our society. Just as we develop medical comorbidity scores, I propose that we should proactively develop individual social vulnerability scores for our patients, so that we can systematically identify and prevent adverse outcomes in the same manner that we deliver preventive medical care.

Second – This encounter highlighted for me that well-meaning public health messages may be less meaningful to some individuals based on their individual circumstances. We must seek to understand the contexts of our patients' lives, or of the communities or patient populations that we care for, so that we can tailor our health messages to create a risk mitigation strategy that they can adopt.

Third – A related insight from this encounter, is that some of our health policies, if implemented in the same manner for

everyone without regard to their social contexts, may inadvertently transfer risk from less vulnerable to more vulnerable groups. An example of that is grocery delivery as part of a stay-at-home strategy which transfers the risk of community COVID-19 exposure from those who can afford to have groceries delivered to those who are working at those frontline jobs.

I am a primary care provider and a health services researcher who has led several of the national COVID-19 equity analyses for the VA. After my encounter with Ms. A, my team examined the role of lack of kitchen plumbing (which includes lacking a refrigerator), lack of other indoor plumbing, and other residential characteristics on COVID-19 infection risk, and found that these non-clinical factors account for some of the racial and ethnic disparities we have observed.⁴ Thus Ms. A is the face of some of the sobering statistics that we hear about, or generate. Her story helps to point to actions that health care providers can take to identify, address, or prevent the high health risks associated with the often-invisible social vulnerabilities of our patients. By seeking to understand them, we can make the invisible visible, and intervene to help.

REFERENCES

1. World Health Organization. WHO Director-General's opening remarks at the media briefing on COVID-19, March 11, 2020. Available at: WHO Director-General's opening remarks at the media briefing on COVID-19 - 11 March 2020.
2. **Newsom G.** Executive Department State of California, Executive Order N-33-20. March 19, 2020. Available at: <https://covid19.ca.gov/img/Executive-Order-N-33-20.pdf>.
3. **Ruiz JG, Priyadarshni S, Rahaman Z, Cabrera K, Dang S, Valencia WM, Mintzer MJ.** Validation of an automatically generated screening score for frailty: the care assessment need (CAN) score. *BMC Geriatr.* 2018 May 4;18(1):106. doi: 10.1186/s12877-018-0802-7. PMID: 29728064; PMCID: PMC5935952.
4. **Wong MS, Upchurch DM, Steers WN, Haderlein TP, Yuan AH, Washington DL.** The role of community-level factors on disparities in COVID-19 infection among American Indian/Alaska Native Veterans. *Journal of Racial and Ethnic Health Disparities.* 2021 Sep 7:1–12. doi: 10.1007/s40615-021-01123-3. Epub ahead of print. PMID: 34491563; PMCID: PMC8422953.

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