

Online Data Supplement

**A Way Forward in the COVID-19 Pandemic: Making the Case for Narrative Competence in
Pulmonary and Critical Care Medicine**

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Restoration by Dr. Rana LA Awdish

The year before I began work in the research lab, there was an incident. Though it was rarely talked about, it was clear it had left its mark on everyone who had been there at the time. Those who remained in the lab were slower to trust. More defensive policies were instituted, as if human carelessness was assumed as a constant.

Prior to even entering the lab, I had to complete a mandatory two-day radiation safety course. The incident was palpable in the undercurrent of terseness in the physicist's tone. It was encoded in the pitch of his voice when he told us we couldn't even begin to conceive of the long-term damage that could be caused by our potential negligence. That we didn't have the capacity to imagine the scope of the risk to the community if we failed to comply. The rules were there to protect us and the community from a potentially lethal and yet invisible threat.

I accepted his assessment and vowed to adhere to all safety protocols, but the first time I turned on a Geiger counter it visibly startled me.

A graduate student in the lab appeared exhausted by my reaction and asked, "So, does *all* data frighten you?"

I shook my head, no, embarrassed by my lack of familiarity with what must have been so basic to the rest of the lab. "But the lab is seemingly so full of radiation," I said.

She softened and explained how normal it was to have a steady click-click-tick of background radiation. She demonstrated, by taking me to a storage area within the lab and holding the sensor near a known radioactive substance, what an alarming rate would sound like. The separate click-click-ticks accelerated and merged into an indistinguishable loud buzz.

Recognizing the value of the tool's ability to clearly distinguish between normalcy and danger where I could not, I softened towards it.

It was in that lab, encased in risk, that our interconnectedness was most apparent. Our collective ability to either prevent or cause harm was a deliberate, daily choice. As we worked behind partitions and often in protective gear, I saw how even the briefest moment of inattention could cause damage. At first, I found the constant vigilance exhausting. Over time, my sense of overwhelm would be replaced by an appreciation of our collective cautiousness as a tacit expression of love.

I would later learn that the incident a year prior involved a researcher in a neighboring lab. He had dropped a fraction of an ounce of radioactive material onto the ground one morning and had not told anyone. He did not initiate any protocol. He had instead just turned off the humming metronome of isotopic decay and walked out of the lab.

The reverberations of his action were both known and are, still to this day, unknowable. The clean-up, by men in biohazard suits, lasted for months. There were the tangible football field lengths of linoleum flooring that had to be taken up, carpeted floorboards of cars that had to be stripped, and a section of off-campus family housing that became a biohazard site. There were rumors of contaminated toys already gummed by babies at the daycare before the office of Nuclear and Regulatory Affairs took over.

I thought about that moment of choice nearly every day that I worked in the lab. I would generate and project possible explanations onto him, though his true internal motivations could not be known.

In one version he understood the magnitude of the problem the moment the spill hit the ground and just couldn't face it. Something akin to an immediate paralyzing fear or shame rose

up in him and meant that the only possible way forward was pretending it never happened. Confronted with what was true, he chose exile.

In another version, he believed he just needed time to think. He could fix it if he could just think it through in quiet. He would take a walk, and he'd come back with a plan that would limit the scope of the damage. Here he was well-intentioned but ultimately ill-equipped to manage a crisis.

The version I returned to the most was the one where he thought first of his family. He feared his exposure would impact his infant daughter, and in a wildly contradictory act, he rushed to pick her up from daycare. He believed so completely in his bodily ability to protect her, he was inured to the reality that his body carried the actual danger. Love as blindness.

If the clean-up had been confined to the square foot of linoleum where it began, there would be little to say. Instead, there were hours and days in which the circumference of impact rippled and widened while nothing was done. The elapsing time meant that the number of people impacted by the damaging force expanded exponentially. They had neither the benefit of awareness nor the time to even attempt to protect themselves.

I'll never know more than what can be inferred from the aftermath of his choice. I'll never know his true motivations, inner dialogue, fears or rationalizations. I'll only ever have my own projections, and a shared slice of the collective fabrications of my lab mates. I cannot tell his story. But I can learn from my experience of it and carry that forward. I've stared at the ripples of his wake long enough to glean something from the waves.

So much time has passed now, roles have changed, and my perspective has shifted. From where I now sit, I know it must have been incredibly difficult for those who lived through the initial incident, given that they were exposed to so much risk and uncertainty. I also know that at the time, it was difficult for me to arrive as a novice to the aftermath of their collective

trauma. It was challenging to have had my early years of training circumscribed by grief and a resignation that bordered on apathy.

The trainees joining our teams now, amidst our ongoing devastation, know this story. They are so perceptive and attuned to what we do and don't say out loud. How we chose to talk about this time, the shape we decide to press our stories into, the tone we use to share them, can be a doorway into a shared space. And it may be in that clearing created with our words, that we find communion and a kind of nascent restoration.

Web of caring By Dr. Megan M. Hosey

The beginning of the pandemic, February 2020, coincided with my return to work after parental leave. My son was just three months old. This coincidence was both a blessing and a horror. On the one hand, I was so busy with patient care, learning about the virus, communicating with teams about how to keep us all safe, and talking with the media about what life might be like for hundreds of thousands of new survivors of critical illness driven by the pandemic, I barely had time to think about my transition away from being my son's full-time caregiver. He was going to daycare every day. In the quiet and slower moments, I ruminated in the company of guilt, shame, and at times, rage.

By June 2020 however my family was finding its groove, balancing our collective responsibilities. One morning as I sat at my desk reading through emails, I was taken aback by several beautifully detailed paragraphs written by Beth, the sister of one of our sickest patients currently be cared for in the intensive care unit:

"My family has been worried sick about Kip and how he is handling this horrid virus, not just physically, but emotionally. You can't image our relief that the Johns Hopkin's team has been so caring and kind."

Kip contracted COVID-19 in his group home, a facility that specialized in the care of adults with Autism and other Intellectual and Developmental disabilities. Kip was cared for by many family members who were relentlessly devoted to him. These persons shared Kip's interests and joys, and knew that Kip thrived in his daily routines and the small pleasures of his life. Beth's email provided Kip's care team with two important things: 1) a means of connection ("this is who Kip is") and 2) instruction ("this is how you can help Kip continue to be who he is"). In learning this, we set to work in trying to re-create Kip's previous routines and gain him access to things that brought him joy. For example, Kip - an avid cat lover - was brought a stuffed cat to his bedside. As someone who thrived with verbal reassurance, our team started incorporating common affirmations that his family and usual caregivers knew that he loved to hear: "You're a good boy, Kip." "Everyone loves you, Kip." "You're doing so great, Kip." As I watched one of our

skilled nurse practitioners whisper reassuringly to Kip while checking his, I found my thoughts drift to my son. I realized in that moment that Beth and I had something in common, that one of the people most precious to us was spending time in an unfamiliar environment. As a new mother during a pandemic, I experienced persistent worry that I was exposing my son to both physical and emotional harm, sending him to daycare where he might be exposed to the virus or to changes in care as a result of the virus (e.g., enhanced cleaning protocols). I rarely let myself think that I was *choosing* this for my son, while Beth had very little ability to dictate things for her critically ill brother. *Was I a monster? What do our decisions say about us when making choices for the most vulnerable people in our lives? How do we pick amongst multiple imperfect options?* Perhaps the best starting place is what we objectively know to be true about our loved ones as this is where we can advocate in helping them be their truest selves.

Kip's body and ICU room had all the usual trappings of critical illness including a tracheostomy, fecal management system, lines, and, perhaps the worst, mitts on his hands to keep him from freeing himself of these devices. Like most ICU patients, he probably had many moments where he felt trapped, frightened, and frustrated. Despite this, Kip found joy in bright colors, animals, and Easter baskets. His ICU room was decorated with pictures of himself, his friends, and his family. A calendar hung on the wall as a reminder of which holidays had past and which were upcoming. Kip **NEVER** missed an opportunity to celebrate a holiday. These objects were deep reflections of love, not just from the staff who took time to show them to him and talk to him about them, but from his inspiring family who carefully collected the "Kipness" of Kip throughout his life and delivered it to his bedside in the face of restricted visitation policy. His face lit up his room as his infectious smile spread in recognition of a familiar voice of a family member (even though virtually).

With intention, I decided to send my son to daycare with his favorite blankets and lovies, snacks, and sippy cups. I hoped that I too could relate my son's sense of person as passionately to his care providers. Mercifully, the daycare's app sends daily pictures of all the children's activities. In those images I saw simultaneously both things that broke my heart, like providers

and children in masks, reminders to stay apart, and mountains of cleaning supplies, but also things that help to mend it, the care that the teachers took to organize all of the rooms and schedules into developmentally and seasonally appropriate learning, and the gentle hands guiding my son into a standing position as he gazed proudly, smiling eyes at the camera. I was and am profoundly grateful for these carers. They love my son, too. The time and energy that they spent caring for my son afforded me the opportunity to care and advocate for critically ill patients like Kip. It is important to acknowledge how different people caring for each other's vulnerable ones provide extraordinary webs of support, each of us creating links for the next person to do their important part. Within this kindness I am able to keep moving forward in the knowing that even though at times we might feel like we are spinning, these webs will catch us, and create opportunities for us to restore our sense of self in the aftermath of the pandemic.

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