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Learning to Blur the Edges during COVID-19: Reconnecting with What Matters Via Narrative Medicine

To the Editor: As medical students swept up in the unyielding current of third year, the abrupt suspension of clerkships due to the COVID-19 pandemic left us with striking stretches of unscheduled time. In response, drawn together by a collective passion for understanding the social context of illness and the role of storytelling in medicine, we formed a Narrative Medicine elective course centered around reaching out to the older generation within our community. With help from faculty at the local Veterans Affairs hospital, we were assigned homebound veterans to call and interview about their life experiences. We sought to improve our history-taking skills while also hoping to alleviate the social isolation we knew to be prevalent in this population. Yet to our surprise, what happened over these few weeks was something much more profound. We became aware of borders that had built up since the start of medical school that threatened to separate us from each other, from our patients, and from our original motivations for going into medicine. Learning to break down these borders, or blur these edges, as we would come to see, was perhaps the most important lesson of them all.

To our relief, the crackle of anxiety we each felt as we picked up the phone and awaited the voice on the other end of the line quickly melted into natural conversation between two strangers. Connecting across age, place, and experience, these calls would remind us of our interest in the well-being of others beyond the checklist of their review of systems. We rediscovered our ability to relate to, learn from, and even enjoy time spent with perfect strangers when provided the opportunity and time. There was no agenda here, no patients to anxiously present on rounds or written examination on the details of their medical history. We allowed ourselves to follow the arc of a stranger's story, letting it bend where it may and continue to its natural, unhurried end. What we heard resonated with and inspired us (Table 1).

Alongside these interviews we scheduled Narrative Medicine workshops to help us delve deeper into the meaning gleaned from the conversations. We endeavored to achieve what Dr. Rita Charon, a founding voice in the field, calls narrative competence, or "the ability to acknowledge, absorb, interpret, and act on the stories and plights of others."[1] We studied paintings and read poetry, hoping we might learn to "reach and join [our] patients in illness, recognize [our] own personal journeys through medicine, and acknowledge kinship with and duties toward other health care professionals."[1] In one of the poems we read, "Monet Refuses the Operation" by Lisel Mueller, we heard Monet tell his doctor:

Table 1. Vignettes from Our Conversations with Veterans

Having navigated the medical landscape of war, a former Vietnam nurse parallels her experiences triaging and treating wounded soldiers to the challenges of our current pandemic. "We are in a war zone, but this time it's invisible bullets. It's even more frightening," she says. Decisions about who will live and die and who will receive the gear necessary to defend themselves are all too familiar. They are memories from another continent, decades ago, now unearthed in our backyards, demanding our attention.
A retired army colonel with New Hampshire roots, he remains sharp in his mid-80s and exudes the warmth of a cherished old friend. He refers often and lovingly to his wife, his high school sweetheart and admired companion for the last six decades. He gravitated toward the armed services at first for "money I desperately needed." Soon, however, he found the connection he had long been seeking. "I made fast friends in the military. I stayed because I admired the people." Relationships, seemingly so difficult to build as a rural working-class 18-year-old surrounded by the wealth and privilege of an Ivy League college, came naturally in the military. It was a community that understood his life and struggles as others had not. In this unexpected place he found beauty and belonging.
A Marine in his 70s served in Vietnam for 2 months, during which time he sustained significant life-altering injuries. He laments the abandonment and loneliness he felt upon returning home but shares his secret for making it through the darkest stretches: "You got to keep positive. You cannot dwell. You got to go on with your life. Dwelling just makes it worse. You kind of put your head on your shoulder and think positive."
A 94-year-old World War II veteran shares story after story, his mind still sharp as a tack although his body is failing. He landed on the Normandy beaches; fought through hedges and trenches; dug foxholes; fell in love with a Jewish woman working with the Resistance in Paris; found his brother lying under a tank during combat, writing a letter to him; surprised himself with how peacefully he accepted death during a gas attack. He has spent his entire life trying but concludes, "It's difficult for me to understand the behavior of mankind," and as he advises me to keep reading about history, his voice takes on a new urgency.

> I tell you it has taken me all my life.
> to arrive at the vision of gas lamps as angels,
> to soften and blur and finally banish.
> the edges you regret I do not see.[2]

It was in these lines that we realized the pre-pandemic rushing, the frenzy, and the desire to outperform each other in the eyes of those who might decide our future had accumulated to create detrimental borders, or "edges," between us. Relationships had veered into the transactional; reductionism and objectivity had crept stealthily in, eroding our ability to connect. Yet Monet's blurry edges were what had drawn us to medicine in the first place. To be a doctor meant shouldering the emotional burden of illness with a patient, listening intently to their stories, sacrificing self through the loss of time, money, and comfort to be intimately present with someone else. We wondered how we might get back to this place.

One veteran I (J.D.) called was initially hesitant to speak to me. I would later learn that he had experienced a turbulent childhood followed by an adulthood haunted by his combat experience. After taking a few days to decide, he ultimately agreed to talk; I settled into my chair and listened. Toward the

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end of our conversation he said, "I was nervous to talk to you. I'm not sure I believe we can ever truly know what it's like to be someone else, to walk in their shoes. But my buddy tells me–and I think I agree–we have to try to let people understand us, we have to at least give them a chance." I heard Monet:

> I will not return to a universe.
> of objects that do not know each other,
> as if islands were not the lost children.
> of one great continent.[2]

We were together in that moment, and the edges began to dissolve.

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Whither the Caregiver?

To the Editor: Back in 2013, I penned on my personal blog the story of my first family meeting after placing my aunt in a nursing home.[1] Over the course of the 1990s, I had followed a fairly typical caregiver path: first paying bills, making sure my aunt had food, accompanying her to doctors, and changing the occasional diaper. That progressed to paid home care and finally to becoming her legal guardian. When I could no longer maintain her safely at home, I found her a nursing home. This is the bookend to that story on my blog.

It happened over the course of a few months in 2001. Then living with severe dementia, my aunt also had a cancerous tumor that was pressing on her orbit (resulting from a missed basal carcinoma). Her primary care clinician recommended surgery to remove the tumor, to be followed by reconstructive surgery. Mercifully, the ear, nose, and throat surgeon recommended what I now know was palliative surgery: going in and removing as much of the tumor as he could to lessen the chances it might break my aunt's orbit. Given my aunt's advanced dementia, the goal was not to cure the cancer but rather to keep her comfortable. The surgery was successful, and soon my aunt was back in her room at the nursing home.

Shortly after that surgery, my aunt stopped eating and was prescribed nutrition shakes. There I was: a caregiver having arrived at the decision point that I dreaded. Should I say "Yes" to artificial nutrition for my aunt with advanced dementia and a slow-growing tumor? Put more bluntly, I was in caregiver hell because this decision was life or death.

After careful consideration of what my aunt would want, coupled with a lot of late-night conversations with clinician friends, I decided to refuse those nutrition shakes, consistent with my aunt's advanced directive—and with who she was. This prompted a request for a family meeting to be sure I knew what I was deciding. Unlike any other family meeting that I attended, my aunt was in attendance. After the niceties, the conversation went something like this:

> *Nursing home*: You know if you stop us from giving her these nutrition shakes, she will die?
> *Me*: Yes.
> *Nursing home*: So that is what you want us to do? Stop feeding her, knowing that she will die.
> *Me*: I know my aunt would not want to live like this, and it's only a matter of time until the tumor comes back. So, yes, I'd like to stop the shakes because that is what she would want.

I am sure there was more to the conversation, but that was the gist of it. We completed the paperwork for palliative care.

The last time I visited my aunt before she died, I found her receiving intravenous (IV) fluids. Even though I knew that the IV was an inappropriate and futile temporary intervention that could have only caused discomfort, I lacked the strength to ask the nurse in charge, in the face of the nurse's own distress that my aunt was dying. That took a phone call from a physician friend to the doctor who had ordered the IV. It turns out no one had mentioned the no-artificial-nutrition-or-hydration order. My aunt died 2 days later, on Shrove Tuesday. I've always thought that was fitting. She loved a good party.

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