

## Experiencing Community in a Covid Surge

by Debjani Mukherjee

I am attempting to organize a pile of ethics consult chart notes in New York City in mid-April 2020. I have been at my job for little more than two months, and in that time, the whole world has changed in response to a global pandemic. I gather the ten cases that I have co-consulted on recently. Nine out of ten of the patients were found to be Covid positive. The virus has infiltrated the ethics consult service, just as it has the hospital and the city. Some people came in for something else and were diagnosed after they arrived. Others came in with acute respiratory distress, and there was little doubt about their diagnosis.

The reasons for the consults are mostly familiar—surrogate decision-making, informed refusal of treatment, goals of care, defining futility. But the context is unfamiliar and unsettling. Our consult service is available 24-7, but to preserve personal protective equipment and reduce the risk of infection, we are consulting virtually. New York is eerily quiet, except for the wail of ambulances. The calm outside is juxtaposed against the clamor of the hospital.

I check my list of patients. Seven out of ten are now dead; an eighth is being released to home hospice. It's unbelievably sad. My fellow ethics consultants and I are experiencing intense and swirling emotions as we accompany clinicians through surges of patients and a disease that surprises us daily with its ferocity. Fear, anger, sadness, and hope come in waves. I can also feel the anticipatory anxiety and grief among my

friends, family, and colleagues, in New York and around the globe. What's next? Uncertainty affects us all. Health care professionals are anxious over real and perceived shortages. Bioethicists are in pandemic mode, dusting off and revising triage plans. Patients and potential patients are fearful—of the disease itself and of the amplification of health disparities and inequities.

There is so much to contemplate, but as I go through my cases, I worry about disability. The pandemic has thrown hospitals and health care professionals into a liminal state between an individual and a community focus, between clinical and public health ethics, a juncture where historically marginalized communities are at risk for further disenfranchisement. I have been hyperaware of the critiques of how triage plans for this public health emergency affect people with disabilities. As I begin my job in New York, I think back to an earlier beginning about sixteen years ago at the Center for the Study of Disability Ethics at the Rehabilitation Institute of Chicago (now the Shirley Ryan AbilityLab). In my first year there, I received a fellowship to study the legacies of disability eugenics in Germany. I vividly remember one afternoon in an archive when, alongside disability studies scholars, I pored over medical records for people with neurological diagnoses who were ultimately sent to death camps. I can't help but wonder what a future disability scholar would think of the choices being contemplated today.

I then mull over what I have learned as a psychologist about biases and frames, or ways of organizing or perceiving information, and about how emotionally charged situations often increase the use of stereotypes and other cognitive shortcuts. There is a well-established critical literature on bias and disability stigma and their impact on health care decisions. Words like “prioritizing” and “triage,” which are ordinary terms on bioethics list-serves, stoke anxiety and foster distrust among people with disabilities. The terms hearken back to a history of health care providers' complicity in perpetuating ableist stereotypes and engaging in quality-of-life determinations.

Thankfully, the disability community is pushing back. In part because of pandemic planning and publicly available documents, robust debate is under way on bioethics list-serves, in blog posts, and in guidelines being created by disability rights groups. Some states are being sued if their exclusion criteria are alleged to be discriminatory. Disability perspectives are clearly emerging. What is less clear is how the aftermath of the Covid-19 pandemic will affect an already-tenuous relationship between many in the disability community and those in mainstream bioethics. I am deliberate in my use of qualifiers in the last sentence. In my twenty-five years of thinking about diversity, identity, and community, the within-group differences of people with disabilities and among bioethicists are variable and depend on context. I don't want to simplify and to perpetuate more stereotypes.

I notice something else in my case notes. Five out of ten of the people live or lived in New York's Chinatown or are or were Asian American. I pause for a moment and take a deep breath. I feel a rush of dread. I have read about the increasing incidence of hate crimes

against Chinese Americans. The misnomer “Chinese virus” has spread and been denounced as racist. I just saw a piece about the business losses in Chinatown on the local news. But I haven’t heard discussion of Asian Americans who are living with the heartbreaking impact of Covid on their families.

I am unnerved by the pair of ethics consults about a couple who had been married for decades and caught the virus at different points in time. They were in the same hospital room, in acute respiratory distress, and decompensating with different time frames, capacities, and potential outcomes. I see now that one of them has died and the other is headed for hospice. The chart said they were Cantonese speaking, and I wonder what the words for *suffering*, *breathlessness*, and *fear* are in their native language. How do you put in any words, in any language, what is going on? I imagine their children desperately trying to deal with the sudden and alarming news of a rapid decline, scrambling to make informed decisions about resuscitation and intubation. They have been unable to visit their parents, to accompany them, and to see for themselves how things are unfolding.

I know I have an extremely small and biased sample, but the proportion of Chinese Americans hits me in the gut. I think back to my days as a grad student doing Asian American outreach for the counseling center at the University of Illinois at Urbana-Champaign. I recall the sessions I led about busting the model-minority myth, or the prevailing stereotype that Asian Americans are the “good” minorities—richer, more educated, more law abiding, more family oriented—than other minority groups in the United States. A case from my list, concerning an unrepresented patient, brings the lesson from the classroom to the bedside. He is a retired restaurant worker and lived in a communal dormitory in Chinatown. He has no family or friends to speak for him and is dying from Covid. His clinical team is advocating for his best interests.

I am consoled that, even in the midst of a crisis, my colleagues looked exhaustively for surrogates and worried about perpetuating inequities. I also think of the health care professionals fearing for their own lives and about the possibility of infecting their families. In New York City, a significant proportion of the health care workforce is also Asian American.

My thoughts on community are more than academic. They are personal. My own family is South Asian, and my parents immigrated from India a few years after the 1965 immigration act that changed U.S. immigration patterns. While Asian Americans are a heterogeneous community, culturally, linguistically, religiously, socioeconomically, and in just about every other way, they share an American experience that coalesces enough to be lumped together by the U.S. government and by academic departments of Asian American studies. If nothing else, this shared experience has given me a perspective on how the bilingual immigrant experience might make the Covid crisis different for these communities.

On a national scale, this crisis has underscored the importance of the communities that individual patients come from. The data about racial disparities is alarming. Deep social determinants of health and the “comorbidities” of poverty, overcrowding, inadequate access to health care, and the responsibility of being essential workers are disproportionately affecting minorities and the working poor. In my old hometown of Chicago, 72 percent of Covid-related deaths have been reported in African Americans, even though African Americans account for less than 33 percent of the population. Similarly disturbing statistics are coming out of other locations.

But even as I think of community-level impact and the categories of disability and race and ethnicity, returning to the individual cases grounds me. Each of us has many identities and communities, and parsing us into demographic pieces erases the nuances and complexities. As the rhetoric of the model-minority myth teaches us,

focusing on group characteristics can encourage an unhealthy competition. In reality, the disabled and the Asian American and the essential worker can all be the same person. You can insert any other category whose intersection with Covid has been studied, such as old age or having medical comorbidities, and none of these are independent variables. Identity and community are not experienced that way or so simply stereotyped.

I recall words penned by the poet Audre Lorde in an essay published in 1983: “There is no hierarchy of oppression.” As a black lesbian feminist, she observed, “I know I cannot afford the luxury of fighting one form of oppression only. I cannot afford to believe that freedom from intolerance is the right of only one group. And I cannot afford to choose between the fronts upon which I must battle these forces of discrimination.”

As this Covid crisis continues to unfold, whether you are a patient from a marginalized community, a health care worker fearing for your own safety, an ethics consultant who has joined a new academic community, or someone from one of many multiple and intersecting communities affected by this pandemic, there are opportunities to forge alliances. By acknowledging both our differences and our solidarity with each other, and not engaging in hierarchical thinking, we can learn from this experience. This crisis has confirmed, more than any other in my lifetime, that our fates are linked. Many of us are already “sheltering in place” to “flatten the curve”—enacting terms that had no meaning to most of us before March. I take a deep breath, feel a wave of hope, and straighten my pile of notes.

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