'Unspeakable, screeching horror': One researcher on the frontline of India's COVID crisis

May 7 2021, by Vyoma Dhar Sharma

Credit: Anton Uniqueton from Pexels

Global health researcher Vyoma Dhar Sharma had just embarked on a fieldwork trip to India as COVID-19 began sweeping through the

population and overwhelming hospitals. It has taken a terrible toll on her country—and her family.

August 25, 2020

It is pouring by the time my taxi reaches Oxford's Gloucester Green bus station. I dash through the rain towards the Heathrow bay as the X90 coach pulls in. The driver gets down to smoke a cigarette and we talk, about COVID-19 obviously. He says he does not know of a single person who has died of this disease. "You only hear it on the news. Frankly, unless people start dropping dead on the street, I'm not believing it."

A few hours later I am on an Air India repatriation flight to New Delhi, flying home for fieldwork. My study explores how global public health policy, scientific research and medical practice affect women's health in India. Global health research is driven by statistical and empirical methodologies, typically sidelining people's experiences of illness and care-seeking within health systems.

And while gender is widely recognized as a major factor when it comes to good health outcomes, the focus on women's health is normally limited to reproductive function. This leads to a systematic marginalization of health issues, such as menopause, uterine prolapse or cervical cancer—all of which lie beyond pregnancy and childbirth. So my work is driven by the need to understand how these issues effect the health of women in countries like India and how they experience the health systems which are supposed to be looking after them.

I break the government mandated quarantine two days after arrival. A little past 10:30pm my masi (aunt) calls, frantically informing me that she just found Nani (my grandmother) unconscious in her bedroom. She was alarmed by the thud of Nani's walking stick and rushed to find her on the floor, next to her bed. Masi is unsure if she slipped or fainted.

The neighbor's son and my aunt somehow manage to carry Nani, 78, downstairs and take her to the hospital. By the time Mum and I reach Ram Manohar Lohia, a government hospital, it is midnight. We sprint past people standing, sitting, sleeping on the pavement and in the stairwell.

Everyone seems quiet. Mum rushes into the emergency room while I wait, watching stretcher after stretcher make its way in and out of the lifts. I read and re-read the Ministry of Health posters on coronavirus symptoms and safety guidelines. Everyone is wearing a mask; some are wearing two. The hospital is packed and social distancing is impossible. Someone brushes past me every other minute.

COVID-19 cases have been rising for months, creating exorbitant pressures on health personnel and infrastructure. In the middle of all this, lockdown restrictions were eased in June. Later in this week, India will witness over 78,000 new cases in 24 hours—then the highest single day increase in in the world.

Hours later I finally see Nani, inert on a gurney, being lifted into an ambulance. She has been transferred to Sir Ganga Ram hospital. After a standard admission test, Nani turns out to be COVID-19 positive. She is placed on ventilator support and spends the next 15 days in the COVID intensive care ward in complete isolation. The doctors diagnose her case as a cerebrovascular accident—a left hemisphere stroke that paralyzed the right side of her body and compromised her ability to speak, swallow and breathe naturally.

September 13

Nani is shifted out of the COVID-ICU. Mum and Masi have been practically living at the hospital. They sleep on the benches in the waiting area. They refuse to eat. They spend the hours chanting for Nani's

recovery. The doctors are contemplating a tracheostomy (when an opening created in the neck so a tube can be inserted into the windpipe to aid breathing) to take her off the ventilator. Other than that, they offer terse, infrequent updates on Nani's condition. Over tea in the hospital canteen Mum is fretful: "They don't say anything, don't tell us anything."

"I read on WhatsApp news," begins an uncle who is joining us today, "that COVID is not a virus, it is a large-scale conspiracy for population reduction." His wife chips in on how the shastras (Hindu scriptures) predicted this kind of devastation hundreds of years ago.

I visit Nani in the ICU a few days after the tracheostomy. She has been made to sit on a recliner. She does not move but looks up when I address her. I am scared of being alone with her. She refuses to close her eyes, insisting that I acknowledge our mutual awareness about her condition. There is a catheter pipe sticking out of her hospital gown, a wide tube piercing her trachea, a nasal feeding pipe, an IV drip on her wrist and an oximeter to measure how much oxygen there is in her blood on her forefinger.

I have never liked the word "vegetative," but my revulsion for it viscerally comes alive that day. In the next bed there is a man weeping and hugging the unconscious body of his father. I swallow the lump in my throat and ask Nani to give me her left hand if she can understand me. She does. I hold her hand in mine, rubbing her arm gently and weakly reassuring her about her recovery. When I leave, I do not have the strength to look back, but I know she is watching me walk away.

September 26

We bring Nani home and set up a room for her. It is still unsettling to meet her gaze when she is awake. For us, her inability to speak is the most painful part. My aunt keeps recounting tiny details from that night

in August—the dinner, the fact that they had a slice of mango each, where Nani's flip-flops were placed, the lights, Nani's exact position on the floor.

My mind goes to Nani's portfolio of anecdotes, the ones we grew up with. With these stories, the charm lies in their out-datedness. For example, a village-based relative who went to Simla (a city in northern India) for an exam and was so gobsmacked at the sight of a light bulb in the invigilation hall that he forgot to fill in his answer sheet. Or people running amok at the sound of a bus horn before they got used to it.

On each visit, I would hug her and say, "Nani, you are shrinking!" That made her laugh.

October 3

I wonder if she finds it odd that all of us wear face masks around her. Does she recognize us? We try to cheer her up. We tell her that summer is passing. We promise to take her to the hills when she recovers. She can hear us because she contorts her face into a baby-like grimace and cries. She makes the same face every few hours when the nurse performs suction inside her mouth and the tracheostomy tube.

The patient monitor beeps at a consistent shrill decibel every other second. At first, it felt as though our collective heartbeats ran with the fluctuating numbers of her pulse and oxygen levels. You could not ignore it. Now, it's clockwork.

I spend most of my time in my room, trying to drown myself in desk-based research, given the restriction on in-person data collection during the pandemic. I send out interview requests to public health practitioners and women willing to speak to me about their gynecological issues and their experiences of the health system.

A senior public health communication specialist I know feels that the progress on women's health is now "two steps back with COVID. Is there any other research happening besides COVID-19? The government wants to hear COVID-19, so everyone is making them hear COVID-19."

Over the next few months, academics try drawing attention to the gendered manner in which the pandemic has compromised sexual and reproductive health; and the physical and mental health implications of working from home in India.

Meanwhile a social anthropologist, based in Uttar Pradesh, and I speak about the impact on women in rural areas. She tells me how antenatal visits had stopped during the lockdown, women were not getting iron supplements or sanitary pads. "No one paid attention to all this during COVID-19," she said.

One can argue that epidemics do not so much create gendered suffering and socioeconomic inequalities but, instead, reveal it. They reinforce inherent issues within global health and clarify the terms and conditions on which women receive care.

In one of my interviews, the head of a Delhi-based sexual and reproductive health advocacy organization says: "The lockdown was the worst phase for unmarried women." Women working or studying in Delhi had to quickly rush back to their hometowns when the nationwide lockdown was announced:

"Many discovered unintended pregnancies … They did not know what to do. They could not tell their parents; they could not say why they wanted to step out. We got calls from Jaipur, we got calls from Delhi to 'help us out in anyway. I can sneak out of my house at 2am to get the abortion done. I'll walk to the hospital.'"

October 14

I reach out to over 40 gynecologists (almost all women) across four famous private hospitals in Delhi and not a single one agrees to an interview. I draw snippets from what my other interview participants tell me about the kind of care they have received from their specialists in recent years. A 27-year-old tells me she once opened up to her gynecologist about having tried to take her own life. "I often wonder why pretty girls like you try to kill yourself," the doctor responded.

Another medical student was prescribed contraceptive pills as a 14-year-old to regulate her periods. When she asked what the medicine was, the doctor told her that "taking these everyday makes a girl more beautiful." No further or accurate explanation was offered. A woman in her early 30s tells me about an exceptionally bad urine infection for which she consulted a doctor online. While the acute pain has subsided, she told the doctor that she continued to feel weak. "Don't be dramatic, if you're not pissing blood, you're fine," the doctor snapped back.

Yesterday, Nani was diagnosed with drug-resistant pneumonia. She sleeps through most of the day and does not respond to our words. Every day after finishing work, I sit beside her. I slip my fingers through her left hand and ask her to grip it. Most of the times she is unable. Unwilling. Today, just as I was about to draw away my hand from hers, she weakly held it. I feel like she asks me to stay a little bit longer, have a little more faith. Her pulse races over 100. I realize I am crying into my mask.

October 20

Nani has not opened her eyes in two days. She is running a fever of 102 and a pulse that jumps between 135 and 33 within hours. Masi no longer

leaves Nani's room. She constantly plays bhajans (religious hymns and songs) on her phone, placing it on Nani's pillow. To me, they sound menacing, not soothing. Around 6pm that evening, I go into the kitchen and find Mum pouring gangajal (holy water, collected from the Ganges) into a small steel glass. "Mummy doesn't look right," she says.

I walk into Nani's room. Someone has put tilak, a tiny dot of sandalwood paste, in the middle of her forehead. There are thin gold hoops in her ears and two pink bangles on each wrist. She has been dressed up. Prepared to depart. She is breathing deeply. No, she is gasping for breath. Mum and Masi hug Nani, whispering belated apologies for harsh words in the past and reassuring her that she can leave if she wants to. We huddle together around her bed. We take turns rubbing her hands and feet. Masi tries massaging her chest. Later, on multiple occasions, she will mention that it felt spongy, filled with liquid. Her pulse drops below 50. Nani continues to make raspy sounds.

The reading on the small pulse-oximeter connected to her finger continues to fall dangerously. The nurse takes a stethoscope and looks for the pulse. She does not say anything. We do not ask. My gaze veers frantically from the oximeter to Nani's face and then rests there. She lifts her head up from the pillow and draws her final breath.

November 11

When the doctors prescribed a tracheostomy, I looked up a few scientific papers on the viability of the procedure in elderly patients and post-discharge care. Poor survival rates were a prominent finding but for Nani, it was also the only viable course of action. However, none of the papers mentioned that when you remove the tube, it leaves a coin-like hole in the throat of the deceased. And as you prepare your grandmother for cremation, the wound leaks yellow purge fluid onto your hands.

On Nani's terhavi(the 13th and final day of mourning), visitors come and go, discussing how and why Nani's condition spiraled. "She caught corona the night they took her to RML." "Was the stroke what they call long COVID?" "The pneumonia was COVID related." "No, it is common when you are on ventilator support." "The tracheostomy caused the infection." When the mourners exhaust opinions on the deceased, they turn to the disease. The common opinion around the room is that COVID-19 is a sham, a made-up disease. I need to get out. I take a taxi to Connaught Place, the large commercial center and tourist spot in Delhi, and start pacing around the inner circle.

An elderly female hawker approaches and pleads with me to buy flowers from her. She is barefoot and speaks slowly. She says she has not eaten since the morning. Nani had not eaten since … I quickly ask her to give me two roses, leaving the flood of thoughts that threaten to devastate me. The roses are wilted, petals dangling off the stem, threatening to fall off in the heat. She offers blessings by way of gratitude, but I do not wish to hear them.

November 20

Question three on my fieldwork risk assessment form: "If the topic area of your research is potentially distressing or emotionally challenging, have you considered how you might cope with the emotional impact on yourself and your participants?"

Response: "Some participants may derive catharsis and closure from the exchange, while others may contend with emotional distress …"

At a time when I do not intend on processing my pain, I begin collecting data on that of others. My request for conducting a small number of in-person interviews comes through. I start visiting a government-run clinic in Delhi. Often, participants offer an apologetic disclaimer about not

being able to talk "objectively" about their health issues because "this COVID atmosphere has had an impact on everything." They have missed or deferred doctor's appointments, ultrasound scans, surgical procedures. They tell me about fibroids (abnormal uterine growths) that are causing prolonged heavy bleeding, painful breast lumps that are making work impossible and recurring vaginal infections that will have to wait for treatment, in a way that husbands, children and household chores will not.

On a cold winter morning in January, a 59-year-old housewife from Shahpur Jat tells me that she obsessively thinks about ways to end her life. She had mentioned that her husband died of a heart attack a few months ago. I ask if these thoughts began after that. She replies: "I won't lie … I did not grieve over him. I don't know what happened to me, I just wanted to die somehow."

She proceeds to tell me about the day he died. They had returned from Pushkar in the afternoon. He went for a bath. They ate lunch together. Napped. He got up and made chai for himself. Then all of a sudden he complained of nervousness. She details how they took him to the All India Institute of Medical Sciences where he was put on ventilator. I go cold at the sound of that word and remind myself to focus. She describes how his oxygen levels peaked to 100 for a bit and the children calmed down a bit. But then he flatlined. I leave my body.

"God gives more daughters to the poor," a young nurse tells me. She is explaining how she helped a frail 23-year-old woman deliver her fourth daughter during the lockdown. She studied nursing for 18 months and is now the village "doctor" in my field site in Uttar Pradesh. She says people would call and beg for her help with home births during the lockdown.

People began avoiding government health facilities as much as possible.

They feared getting tested or worried that they would be taken away by the police if they tested positive. She does not wear a face mask and I ask her why. She says she stopped wearing it after her mother passed away two months ago. She does not care about anything anymore, she says. The interview questions dry up inside my mouth.

Last week, I walked in on my mum sitting in Nani's room, sobbing. All of us have occasional dreams about Nani and we tell each other about them. But Nani does not speak in our dreams either. Masi no longer brings up that night as often. But now, every time it comes up, there are less words and more tears.

April 26, 2021

Earlier on the day of Nani's death, I was watching a Royal Society webinar featuring Stephen Fry and Venki Ramakrishnan. Fry defines science as "humility before the facts." For me, this doesn't simply signal the value of evidence per se, but a radical re-examination at what counts as evidence in the first place. And on whose command? Fry insists that: "Science can look at how people believe and why they believe and why they can be pushed into believing things that are untrue and why they find it hard to accept things that they don't want to be true."

Global health prides itself as the objective, apolitical, evidence-based domain of eliminating diseases and saving lives. In extending "criticality" (or the need to question all assumptions) to the field of global health, one risks accusations of nitpicking without offering answers. Criticality engages with the historical context of a problem. It pushes against the limits of what counts as evidence and questions who is in command and who has been silenced as a result.

The neurosurgeon and writer Paul Kalanithi said that your relationship with statistics changes when you become a statistic yourself. What

happens when the numbers can no longer contain the evidence? Despite being a multi-million dollar, centuries-old enterprise to alleviate suffering and measure impact, global health still finds pain an unquantifiable human experience.

On March 24 2020, a nation-wide lockdown was announced in India. Delhi had 30 confirmed cases that day. By May 7, 2021, the city had more than 90,000 active cases and 18,398 deaths. Diagnostic labs are severely short on testing capacity. Hourly notifications are coming in of hospitals running out of oxygen.

Morgues are overflowing as around the clock cremations and burials are becoming insufficient. People are dropping dead on pavements.

Delhi went under lockdown on April 19 2021 with record breaking daily spikes in infections and deaths. When the prime minister addressed a highly anxious nation on April 20, he spoke for 19 minutes and barely said anything. The government is refusing external assistance. It is also denying public access to data on severity and patterns of the disease.

It has been observed before that our extensive capacity for language distinguishes humans from other animals. But our pain distinguishes us from language. Not because pain silences words, but because it surpasses them. Our subjective experiences exceed measurability and cannot be generalized. All of the dreadful statistics coming out of India relate to people and to suffering.

In New Delhi today, each individual loss, each burning pyre is an unspeakable, yet screeching horror. It is testing the boundaries of what can be said. What should be said. It is testing the boundaries of evidence.