Syndemic in a pandemic: An autoethnography of a COVID survivor

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Abstract
This paper provides my personal experience as a COVID-19 survivor during and postrecovery periods. The stigma that my children and I underwent exposed us to the fragility of a social system that we struggle with all through our life to remain a part of. My story revealed a strong symbiotic relationship between the disease (COVID-19) and the patient's low acceptance in society, primarily attributed to misinformation and xenophobia around the COVID-19. This autoethnography speaks for several other COVID survivors who met with the same fate of being discriminated against and stigmatized. As a COVID patient and survivor, the traumatic experience was creating a fear psychosis in me, the effect of which I presume will stay beyond COVID-19. This condition of a syndemic seems to linger and negatively affect my outlook toward society. If COVID survivors develop a syndemic condition in a pandemic situation, it will require significant efforts to reserve it or sometimes even become irreversible.

Key Words
autoethnography, COVID, culture, pandemic, stigma, survivor, syndemic

The first incidence of coronavirus infection (COVID) in India was identified at the end of January 2020, and it spread widely by March 2020. There were four national lockdowns announced by the Government of India from March 25 to May 31, 2020 to control the spread of the virus. In these 68 days, a complete shutdown of all activities (economic and noneconomic) and strict stay-at-home orders were observed, permitting access only to essential services—food and health. This was the first time a population of 1.3 billion was asked to stay indoors for at least 3 months.
The isolation, the fear of death, and associated stigma (if infected) caused a lot of mental distress and agony among adults and children alike during the lockdown period (Sahoo et al., 2020). Although India was struggling with meeting the required number of COVID tests and providing health care facilities for infected patients and their survivors, by June 2020, the stringent lockdown relaxed, and people were permitted to move about, although only during specific periods in a day.

COVID-19 invoked mental health problems in all three phases of lockdowns: social isolation during lockdown; stress, anxiety, and fear when tested positive (self-stigmatization); and social discrimination of survivors as carriers of the virus (MoHF, 2020). All three phases were laden with psychological trauma and emotional challenges emanating from the fear of getting infected, trauma after being infected, and exclusion, discrimination, and stigmatizations after surviving the infection. Collectively, experiencing these three phases caused a syndemic in a pandemic. A syndemic is a situation where two or more epidemics coexist and exacerbate one another’s occurrence (Druss, 2020). It is different from comorbidity, which is a biological condition. Instead, a syndemic is a more structural disease caused by the acts of discrimination and stigmatization inflicted on the patients (World Health Organization, 2020). In other words, it is a form of the disease caused by the influence of social, economic, environmental, and political context on a section of the society (Shiau et al., 2020).

In the following sections of this paper, I will narrate how my young children and I went through all three phases of self and social-stigmatization, which offers a glimpse into some of the social and psychological effects provoked by COVID-19. On December 1st, 2020, India had 9484,506 individuals infected, with 137,933 succumbing to the virus and 8915,158 having recovered (Worldometer, 2020). My story provides a peek into the life of an individual who survived the pandemic but could not survive the syndemic—a phenomenon with which many others in India could likely relate.

I am a mother of three young children, working as a university professor. Due to the lockdown, educational institutions were physically closed but allowed to remain open virtually, and so schools and colleges conducted regular classes online. The lockdown rules restricted anyone from coming out of their houses except to go to the hospital in emergencies. The rules also prevented maids and other support staff from coming to work. To ensure safety for everyone, no one could and wanted to visit anyone during the lockdown periods. In the beginning, it was fun staying at home and spending time together, working in a relaxed manner, and watching movies for entertainment. But as the days passed by, boredom and monotony started setting in. We all were desperately waiting for the lifting of lockdown so that people could physically meet each other. There was a sense of realization—how much we need each other’s presence for our mental and emotional wellbeing.

The positive side of the story was that we saw lots of monkeys in our apartment, different kinds of birds, and beautiful butterflies. This was the first-time children saw animals so closely without having to go to the zoo. The Internet played both positive and negative roles in our lives. It suddenly became an inseparable part of our life—we worked on it, we entertained using it, and we met friends on it. The fallout of the Internet’s extensive use was addiction among children and too much and too early exposure to things not meant for children, resulting in developing deviant behaviors (Shah et al., 2018). For example, my third daughter, who is about 9 years old, was looking for the meaning of the word gender for her school assignment on Google. The research gave her many meanings, including sex and sensual behaviors and links to the images. These made her very curious to understand what the images meant, and she went on a journey of exploring them and eventually landed on a pornography site.

In July, when the lockdown eased a bit more, I started going out in the evening to buy some vegetables and other items for our house. I religiously confirmed the mandatory precautions laid down by government—wearing a face shield, face mask, and gloves, which, if not followed, attracted penalty and strict punitive actions.

Around the same time, the health inspectors of BBMP (Bruhat Bengaluru Mahanagara Palike-Municipal Corporation of Bangalore) visited apartments and tested every individual residing in the jurisdiction under their control. On the day of the testing at my apartment complex, the officials arrived with the testing kits and informed the residents to come with their family members to give samples, one after the other. In the last 3 months, this was
the first time neighbors saw one another face-to-face and smiled at each other; otherwise, it was only through WhatsApp that people exchanged information and greetings.

I went down with my three daughters, and we gave our samples to the officials. The officials informed us that the results would be available after 48 h. The wait for all of us brought a lot of anxiety and stress. The question that lingered in my mind was: What if it was me who had the disease? Are we in a safe neighborhood? How will my neighbors treat my family and me if we test positive? Will I be seen as the person who will be responsible for any danger to others' lives? Can I continue living in my house, or will the officials take me from here and put me in a hospital? I was grieved with shock, solitude, shame, internalized stigma, fear of infecting near and dear ones, and self-directed anger and curse.

The only way to handle this anxiety was to stay calm and keep ourselves distracted with Netflix and YouTube. There was inherent attention occupying my thoughts about what if I was found positive?

Two days later, my children and I were tested positive—asymptomatically positive! The news spread like fire, not only in our apartment complex but in the entire neighborhood. The government authorities put up a barricade on the two ends of the street so that people from other communities know that the restricted area had COVID-positive patients and should avoid going there. Our apartment was sealed, and we had stickers outside our house that mentioned COVID-positive patients in red. Our zone was named a red zone, and a high alert was announced. Instead of helping us during times of grief, the government's efforts brought a stoplight on my children and me instilling additional fear in the neighborhood. I clenched when I heard that my children are infected with COVID-19 as its effects on them were, at the time, unknown.

I live on the third floor of an apartment complex with two other apartments on the same floor. The access to our apartment was blocked, and we were asked to stay indoors at all times. Any food items that we needed were ordered online and delivered by the watchman stationed outside the apartment complex gates. The apartment association asked us to retrieve our delivered items only after the watchman left the floor. The association used WhatsApp to coordinate and control the movements of my daughters and me.

My children and I had no problems following these rules because we felt the responsibility to others. Twenty days went by with no contact with the real world. The only contact we had was with the virtual world. Lots of messages from relatives, friends, and neighbors poured in. We always thought once this phase passes and we are cured, the situation will improve. Less did we know that we were utterly wrong. Illness is proven to create a stigma around itself (Bhattacharya et al., 2020) became real in my case.

Our neighbors repeatedly asked the authorities to admit us to the hospital, but since we were young, non-symptomatic, and had no comorbidities, we were permitted to stay at home but under strict policing. The isolation up to this point was understood, but its never-ending extension was confusing. Slowly our health condition defined our relationship with others. We had become the most unwanted family in the complex. People started talking about us as the family that carried some curse from previous birth. Rumors propagated how God had infected us with COVID due to our misdeeds in past lives and misfortune in the present life. Suddenly, the people who messaged us that they are with us in all our difficulties slowly withdrew from wanting to associate with us. Our neighbors refused to send the watchman to our house to drop the groceries off. We had to survive on food that we stored during the next 2 months (July and August). My parents-in-law, who lived in a small town in another city, could not travel to help us in this situation due to their age and nonavailability of interstate transport. They were so worried about us that they tried calling several of our neighbors and asking them to support us with basic requirements. The neighbors made promises but did not follow through with their actions!

Amidst all of this, an elderly neighbor who was 92 years old died in the building—he had not been keeping well for a very long time. Our neighbors believed and propagated the idea that the coronavirus traveled from our windows and infected and killed him. We were immediately asked to shut all of our windows and doors. Even the only place to get some sunshine and fresh air during the height of the crisis times was being denied to us. With every day passing by, we were only ostracized and expelled from the community.

We religiously followed the medical treatment and regulations implicated on us for 21 days. When BBMP health officers came to test us on the 21st day and told us that the test results would be known in another 2 days, it
brought a sigh of hope and relief since we were happy to have survived the disease. However, we did not know whether we will survive the indifference of people we lived with for more than a decade. In the last 10 years, we had shared food and festivals, troubles and tribulations, and happiness and success with each other. My house was a house that anyone could come to anytime for anything they needed, and we were always happy to be of help and support. I could not believe that one day this will be the most stigmatized house in the complex.

After a month of complete isolation, I went onto my terrace to dry some clothes. Coincidentally, one of the neighbors living in the apartment close by had also come to dry her clothes in the sun. I was so happy to see her and greeted her from afar. But as soon as she saw me, she just ran away from her terrace screaming: “How could someone be so insane to come to the terrace to spread Corona?” Immediately a group WhatsApp message was sent to all the residents—“She was spotted outside her house.” I replied in the group that my daughters and I had been cured and uploaded the most recent COVID test results confirming this point. But this effort was all in vain. Everyone demanded that we stay inside our home and not come out until they feel safe around us, even if we were no longer positive. It made me realize as your vulnerabilities increase, so does your victimization increase (Abigail & Susan, 2009).

Two months went by, and in October, the most important festival for Hindus, Diwali, was celebrated, which marked the start of a new year, and was welcomed by the lighting of lamps and firecrackers. This is the day when neighbors visit each other at home and exchange greetings and sweets. We forgive any wrong that may have been previously done and begin with a fresh and promising start. Diwali came and went, but no one even remembered we existed—good wishes, neither real nor virtual, were sent to us. People started hating our presence in the community so much that they explicitly told me not to celebrate Diwali as it is not a good year for my family and me. I tried to let it pass by telling myself that these individuals’ behavior reflects their fear rather than hatred.

Nonetheless, I could not help but feel that they each valued their (and their family’s) own perceived safety while entirely disregarding others. For their wellbeing, they did not mind directing pain to others. My children, aged 14, 12, and 9 at the time, could not understand the community’s severe reaction.

Even today, we cannot use the elevator or talk to any of the neighbors. Everyone looks at us as the family of unfortunates rather than the family of COVID survivors. Even after governments’ efforts to create awareness that COVID was not a disease that survivors can spread by talking or seeing each other from a distance, stigma toward survivors remain. The myth about HIV as a contagious disease that can be passed along by touching and talking was also applied to Corona. The community members believed that God chose my family to punish us, so it would not be wise for them to go against God’s will. A few educated individuals also fell victim to this groupthink, and they too accepted the prevailing belief even if it was against their better wisdom. Children in the apartment started avoiding my children since their parents gave them explicit instructions not to engage with my children. It was a shock to see that the innocents’ minds were indoctrinated to spread fear and hatred toward survivors of a disease. Shopkeepers in the same locality refused to sell things to us and asked us not to visit their shops so that their business does not get detrimentally affected. They feared the loss of business but did not fear inflicting hurt and pain on a discriminated family.

These behaviors added to our stress of just recovering from a disease, isolation, stigmatization, and penalization for committing no sin. The pandemic slowly created a syndemic in my children and me. For my young girls, this was the first time they were exposed to the mediocrity and hypocrisy of the community and the general public. I am trying hard to avoid my children developing a hatred for society, neighborhood, and humanity.

I have heard of discrimination between classes (rich and poor), ranks (upper and lower), and genders (men and women). This was the first of its kind discrimination based on health conditions among the similar classes and strata of the society. I had never imagined that my health condition one day would be used against my children and me, and, based on this fact, we will face discrimination. My exposure to discrimination made me understand how people feel when they experienced the emotions of being less valuable than others. This challenge provided me with an opportunity to understand the need for self and social resilience.

My story is an unexpected revelation into the lives of many who have experienced the stigma that transcends the scientific understanding of COVID-19. This is further aided by misinformation and xenophobia during
pandemics (Prasad (2020), Bhattacharya et al. (2020)). Infectious diseases and stigma share a symbiotic relationship, especially in countries like India, where stigma plays a crucial role in organizing society. As the COVID-19 cases rise in India, the role of stigma in compounding the disease’s social effects is critical to understand. The stigma associated with COVID-19 is real and here to stay unless we take sufficient actions to curb it.

The failure of social and political institutions in controlling the panic that created a stigma for the disease is the reason behind my painful experience with my community during the most vulnerable part of my life. Should we all be prepared for a syndemic every time a pandemic strikes? Or will we be able to rise above our fears and place humanity over the myth of self-safety. When I look back, it makes me feel how the COVID situation was unnecessarily exaggerated to make me feel helpless and weak. This could have been reversed if the pandemic was well understood and explained to the general public and communities that housed victims like me.

Drawing from the introspection of my personal experience with stigma and discrimination, I can extrapolate it to understand how much an individual is entrenched in society’s prejudices (Prasad, 2019) that it disallows them to develop a feeling of repulsion. I allowed myself to be subjected to stigma so that I remain a part of society. The stigma toward the COVID-19 survivors embedded in the societal structure and social phenomena was causing pain and hurt, but my inclination for social inclusion made me take this pain and accept these prejudices as a normal practice instead of questioning or challenging them.

My desire to be a good part of a society dominated my options to allow stigmatization and live with it. Someday when my health restores to normal, I can reclaim my previous position as an accepted member of society. I was lucky that it was a stigma associated with a curable health condition that had recourse, unlike other types of stigmas. Like any other ordinary person, I denied acknowledging the existence of an alternate solution and saw myself trapped in my own making of accepting humiliation as normal behavior (Mandalaki & Fotaki, 2020). The community around me succumbed to their fears, myths, and rumors around COVID-19, which made social stigma an acceptable social behavior (Bhattacharya et al., 2020). I preferred to understand the community than understanding myself.

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Syndemic in Pandemic

Will we let him die or murder him?

Xenophobia or Xenophilia

We are losing people due to COVID-19.

Stop giving reasons to them.

Exclusion

Don’t leave me alone and let me down.

Will COVID kill me or me?

Kill all of them.

I am one among you.

Physical distance to mental distance.

Don’t talk to him or his family. They will infect us.

Don’t allow them in the hospital.

Throw the family out of the apartment.

Exclusion

Murder me!

Will we let him die or murder him?

Stop giving reasons to them.

Exclusion

Don’t leave me alone and let me down.

Will COVID kill me or me?

Kill all of them.

I am one among you.

Physical distance to mental distance.