Exploring an unsung stigma factor in COVID-19

Dear Editor,

Pandemics remind us how connected we all globally are. The worldwide COVID-19 case burden rightly points toward this connect. Associated with every pandemic is stigma, which is actually an evolutionary response for survival among humans. While on the one hand, we have scarcity of viable therapeutic options against SARS-CoV-2, on the other hand, there is an abundance of information available at our finger-tips, courtesy technology. It’s as if the coronavirus is a crown, sitting on our heads constantly. The ever-increasing numbers indicate towards the deadliness of the virus and without us knowing, are actually adding on to the stigma.

In today’s scenario of lockdown and social distancing, we are using Internet more than ever and this has led to exposure to too much information (TMI effect). On doing a google search with the keywords “COVID-19 numbers,” we get links to numerous dashboards and media channels, all full of numbers written in bold and highlighted in red- the number of active COVID-19 cases, which is being updated every second, every minute and every hour of the day. Different dashboards display different numbers leading to information overload-induced paranoia. The staggering large number of cases coming up every day makes us feel overwhelmed and powerless; in spite of being totally healthy we feel anxious and mentally fatigued. The numbers are being imposed on us without being sought for, through our mobile devices and laptops—the “Always-on syndrome.” It’s difficult to judge the credibility of the sources when too much information is coming through the homogenizing lens of the Internet. Often, number of positive cases and death toll pops-up on our screens, while browsing through our news feed, a phenomenon termed as Information Scanning. The media doesn’t highlight the number of recovered cases as much. This, combined with the unavailability of viable treatment options, leads to an image of permanence being imprinted on our minds. If somebody we know, comes out for, through our mobile devices and laptops—the “Always-on syndrome.” It’s as if the coronavirus is a crown, sitting on our heads constantly. The ever-increasing numbers indicate towards the deadliness of the virus and without us knowing, are actually adding on to the stigma.

We have very little information about the virus and the course this pandemic is going to take. We have limited idea when the surging numbers are going to take a downward turn or when will our lives return to normalcy and all this is culminating in “the fear of the unknown.”

Military metaphors like, “target,” “battlefield,” “victim,” “frontline warriors,” “killer virus” etc., impart an apocalyptic feeling in the minds of the general mass. It gives a perception as if the “numbers in red” indicate “civilian casualties.” All of this leads to two different forms of stigma- internalized, i.e., having a negative perspective towards a particular group(s) of people and anticipated, i.e., fear that one might become a part of that group in future and experience discrimination and bias.[4] To prevent and address social stigma, WHO has formulated a guiding document suggesting that “Words matter.”[5] They recommend that terms such as “victims” or “COVID-19 cases” be replaced with alternatives like “people who have COVID-19.” Further, the contact tracing of the positive cases appears like an interrogation where they are asked how many and who have they come in contact with. This creates unnecessary apprehension. As per a few newspaper reports from different parts of the world, even people who have recovered are being shunned by the society, indicating that, “More than the infection, it’s the stigma that hurts.”[6]

These people are being subjected to badgering and threats and even online bullying.

We are making the numbers the protagonist in the situation by checking and emphasizing on the live updates for COVID-19 every now and then, but such hasn’t been the case for other communicable diseases like tuberculosis (TB). With an R0 as high as 4.3 (as reported in China in 2007),[7] a global incidence of around ten million and a global annual death of 1.5 million in 2018 with over 4000 deaths per day,[8] the stats are in favor of TB being a more communicable and lethal infectious disease as compared to COVID-19, which has an R0 of 2.2 (95% CI, 1.4 to 3.9)[7] and a case fatality rate of 4.03%.[8]

But we, the general public, are not talking about TB every day. The reason behind this is the absence of dashboards and media propaganda around the “numbers in red” for TB. Although the horrifying numbers are good enough to induce anxiety among people to motivate them to stay indoors, but is it not likely to increase the stigma and demotivate them from coming for testing, even if they are symptomatic? The day the live updates stop being touted on different media, the fear will surely attenuate. The increasing case burden, representative of a pandemic, induces panic, while over a period of time, if a disease becomes endemic, the panic gets mentally ended, just like TB. This goes on to show the unsung impact of numbers floating in front of our eyes at every moment.

One of the oldest examples of the stigma surrounding communicable diseases can be traced back to the early 1900s, when Mary Mallon was diagnosed with typhoid fever.
After months of public health investigation, when she was confronted with the evidence and requested to give a urine and stool sample, Mary attacked the investigators with a carving fork, her defence being that she was asymptomatic. The legacy of Typhoid Mary gave rise to the concept of super-spreaders, i.e., asymptomatic carriers for a disease. Such stigma still exists. Today, there are reports that people with COVID-19 who have recovered from the disease, when tested again, are coming out to be “positives” for the second time, despite showing no symptoms. Very soon, this might lead to a fear of even the “numbers in green” on dashboards, which are indicative of number of people who have recovered. This would cause anxiety among public, of anybody and everybody, besides “those reds,” aggravating the stigma and thus disrupting social cohesion.

It is apparent that COVID-19 is here to stay and hence we need to have a structured approach for handling it. In future also, there might be similar respiratory illness-related public health outbreaks caused by other viruses and there should be global preparedness to deal with the same. We need to take our learnings and experiences from this and earlier pandemics forward and formulate national programmes for the prevention, control, and management of such illnesses. Besides, we need to tackle infodemic within a pandemic and strategize how only credible information reaches the general public to prevent stigmatization. When we are busy trying to eliminate the virus, we don't want the fear of numbers adding on to our challenge. The constantly ticking clock of numbers is like an indication towards the impending danger and we need to handle this very sensitively.

Although “words do matter,” we suggest, “numbers matter even more.”

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