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Perspective

“Tamaso Ma Jyotir Gamaya”: Covid-19 and Issues with Disability

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ABSTRACT

The viewpoint of disability is important for comprehending and building social justice for everyone in the society. However, despite this fact, public health experts and policy makers choose to ignore this viewpoint. The understanding of the disabled and their disability rights is equally important in terms of Covid-19 policy-making process. This research article attempts to look at the disability ethics, understanding the discrimination in the structure, to inculcate respect for disabled and develop ways to safeguard the disabled community in the coronavirus pandemic. During such crises of care, the allocation of resources is not being done appropriately according to a disabled person's requirements and quality of life. There is a need to avoid the stereotypes about disability while providing educational or medical facilities. Recruiting more professional healthcare workers, teachers, and accessible reading material that can be helpful for the disabled people is important at this point of time. Removal of prejudices and safeguarding of the equal protection of every individual's interests, including those with disabilities is what this paper would analyse and discuss.

Key words: Clinical ethics, COVID-19, Disability studies, Disabled persons, Health equity, Resource distribution, Social justice, Depression, Anxiety

1. INTRODUCTION

People with disabilities are one of the most excluded and marginalized groups in every society. They face everyday discrimination in the form of pessimistic behaviours and attitudes. Due to lack of adequate legislation and policies, they are explicitly barred from the policies of education, rights and healthcare. Observing the impact of COVID-19 on the disabled community, it appears to be very severe. Many problems have been

studied related to people with intellectual and developmental disabilities. They face disruptions in their routines and are impacted by behavioural changes. While health literacy is seen as an important aspect of education for abled people, disabled people are side-lined in this area. Moreover, there are no accessible medical tools and medicines available for them. People with disabilities are constantly searching for information related to their risk of exposure to the COVID-19 (Devandas, 2020). The existing studies focus on literature about testing mortality rate of people with disabilities and their treatment during the pandemic. However, this paper provides an analysis of the living experiences of people with disabilities diagnosed with COVID-19 and who were isolated in the wards, in order to have a good hold of the narratives that include the challenges and problems faced by disabled people during this ongoing pandemic. Many mothers, caregivers, healthcare workers, disabled adults and children have been interviewed during this survey and their personal experiences have been recorded in this article.

2. WORLDWIDE DISCOURSE ON COVID-19 AND DISABILITY

In the article, Disability inclusiveness of government responses to Covid-19 in South America by Ana Paula and Elena S., the discussion revolves around the disability inclusiveness of governmental responses and policies in South America (Malfitano et al., 2020). The article by the United Nations Covid-19 and the Rights of Persons with Disabilities examines the very early stages of COVID-19 pandemic and the lacking perspective of the current times (2020). The article Clinical Management of Covid-19 by World Health Organisation talks about the barriers which are discussed from the point of view of the doctors and healthcare workers and the perspective of the disabled people is again absent (2020). Devandas in Covid-19: Who is protecting the people with disabilities, and even in other research, the discourse is mentioned about persona with disabilities through an able person's point of view and the area of specification is also very limited (2020).

The perspective in this article is that of the disabled and it has been evolved by the disabled people. It focuses on the real-time experiences of disabled patients diagnosed with COVID-19. As educationists, we tend to focus upon and discuss the challenges of disabled students and teachers from school to higher educational institutions. It also

comprises a lack of accessible medical equipment and drugs for disabled. It focuses on the emotional needs of disabled in the pandemic times and tries to provide further solutions to the matter of governmental policies that are also disabled friendly and that could resolve their problems in these harsh times. This article does not only articulate the problems of disabled but it tries to project ways through the disabled eyes to understand the issue and how it can be resolved.

3. INTRODUCTION TO COVID-19

The infectious disease of COVID-19 caused by the recently discovered CoronaVirus is a large family of viruses that causes illnesses among humans by impacting them with serious respiratory infections. The Wuhan Municipal Health Commission in Wuhan City reported several pneumonia cases that were linked to Wuhan's Seafood Wholesale Market on December 31st, 2019. The market was immediately shut down. Wuhan City was completely locked on January 23rd, 2020 prohibiting all the travels and movements in the city. With this, on 30th January 2020, the World Health Organization (WHO) declared the outbreak of the virus announcing the public health emergency worldwide. Cases of Novel CoronaVirus were spreading with every passing day in several parts of the world. Hospitals became the main area of transmission of the virus as COVID-19 was mainly being identified among the patients and healthcare workers. After the realization of the massive spread of the virus, on March 11, 2020 WHO declared COVID-19 as a global pandemic.

The COVID-19 pandemic is said to be the most crucial calamity faced by humankind since World War II (Phelan, 2020). Currently, the outbreak has affected twenty-seven million people and more than a million people have already succumbed to this virus and have lost their lives. Till now, there is no information on vaccines or drugs which are clinically approved and could beat this virus. The pandemic has spread rapidly around the entire world impacting the health, economy and social status of the nations. The loss of lives has caused severe damage to society. The virus poses a major health concern for the human population resulting in hospitalization and massive deaths, especially of people belonging to middle and old age groups. However, not only the health but also the economy of so many powerful nations are facing challenges and a threat of massive inflation. Talking about society, the COVID-19 outbreak has majorly

affected the vulnerable sections of society the most. People living under extreme poverty, old people, migrants and people with disabilities are facing the biggest challenges of this pandemic. People without homes who reside under shelters are exposed to this threat. Daily-wage workers who work in the construction or manufacturing industries faced severe challenges during the lockdown with no income and food.¹ Older people are highly vulnerable and are at risk of being exposed to the infection majorly due to their pre-existing health conditions such as cardiovascular diseases or diabetes.²

4. COVID-19 Precautions: A tough task for the Disabled

In the entire narrative that the popular media carries to the audience referring to the impact of COVID-19 on people, the narrative of people with disabilities is missing. Even during normal times, due to the lack of affordability and availability, people with disabilities experience difficulties, in terms of accessing basic health-care amenities. Even today, there is inaccessibility of medical equipments which are friendly for people with disabilities like talking oxy pulse meter, talking thermometer, or even basic medicines for disabled people. Several other issues aggravate the risks of infection from COVID-19 for people with disabilities. Sheer disruption in the support and services, not being included in the common health provision or being provided adequate information related to COVID-19 are some of the challenges faced by the disabled community. Moreover, due to some pre-existing health situations, it leaves them more vulnerable to developing a serious disease, and surviving in a world where accessibility is limited and there are challenges to procure goods and services, it brings them to a state where they are completely neglected.

The provision of individual self-care and various preventive measures against the COVID-19 outbreak entails many challenges for people with disabilities. Many of them face difficulties while following the measures to secure themselves from the virus which includes maintaining proper personal hygiene, frequent cleanliness of surfaces and their places. Due to physical impairments, various environmental barriers and

¹ (Business Today, 2020)

² (European Centre for Disease Prevention and Control, 2020)

inadequate services, cleaning homes and washing hands after every short period of time is a challenging task for people with disabilities. Many of them fail to follow the social distancing norms or feel anxious to isolate themselves because unlike abled people, they seek regular support and help from outsiders to fulfil their every-day self-care activities.

4.1 People with Autism

Many autistic people suffer from co-occurring physical impairments as well. They are known to have severe chronic illnesses and medical conditions. They also depict atypical immunity, and many autistic people and their families have autoimmune disorders as well. All the factors mentioned above bring them closer to the threats of being exposed to COVID-19. They also tend to witness the sheer terror it brings along with it. Access to appropriate health care is a challenge for autistic people during normal times as well, and even now, during the pandemic the healthcare workers and services are almost at the breaking point where considering accessible services for autistic people is barely a priority. The crucial reality is that healthcare workers tend to prioritize the lives of abled people to be saved more than the lives of the disabled people.

For many autistic individuals, particularly children who also suffer from intellectual disabilities, find it difficult to understand the present situation of the pandemic and its impact. For this group of people, the time is proving to be extremely challenging. With constant and conflicting changes in governmental and state plans and advice, which are not provided in the accessible formats, are creating bigger hassles for such people. Therefore, autistic adults who have intellectual disabilities are left aloof from the vital public health information and services. Moreover, with a sudden change in their safe and comfortable routines, they tend to experience more anxiety and stress.

People are becoming unemployed due to the impact of COVID-19 on the economy. Many autistic or disabled people are the primary groups of people who are on the verge of losing their jobs. Moreover, they cannot ask their employers to be at home because, in the end, it brings them closer to the possibility of losing their jobs. In places like Rajasthan, the online mode of working is still at bay and disabled people, too are

expected to work from offices. Traveling through public transports can bring them closer to the threat of being exposed to the virus. Moreover, while being out, they can't manage without any assistance or help. Renowned disabled activist, Lalit Soni, before his demise, mentions that to save the disabled community from the pandemic, there is a need for the state governments to follow the strict guidelines introduced by WHO and the policy structure made by the Central government should be followed nationwide. The criteria of being at home and to self-isolate are said to be ideal. However, it is true that for autistic or disabled people, this brings huge changes in their lives. In a world that is inaccessible to them, self-isolation or social distancing seems far from ideal for them. For disabled people, being self-isolated feels like they are being forced to do something that is extremely anxiety-driven for them. Many autistic and disabled people tend to face exclusion, bullying, abuses and harassment at home which makes the criteria of being at home for them extremely depressive and unsuitable. Therefore, there is a need to enlighten people, for healthcare workers and doctors to be more empathetic and inclusive while interacting with disabled people.

4.2 Students with Learning Disabilities

The COVID-19 pandemic has impacted people with learning disabilities as well, who in fact, already face social and educational disadvantages (Phelan, 2020). Due to the pandemic, many students with learning disabilities are seen to be out of school. With the school closures, the educational system has now turned to the online mode of instruction to continue the learning. However, due to the inexperience of teachers to prepare content for disabled students there is a huge impact upon the students with learning disabilities as they feel left behind. Due to their learning disabilities, they tend to face challenges in terms of accessing public health information, basic hygiene measures and adequate health facilities. Especially, girls with disabilities are seen to be experiencing a biased treatment in such situations fighting both the norms of disability and gender every day (Devandas, 2020).

4.3 People with Visual Impairments

To slow down the unprecedented outbreak of the virus, the pandemic which brought an emergency lockdown nationwide carried a serious impact especially on people with

visual disabilities that endangers their lives in today's world. The restrictive and control measures recommended by the government that include the novel behavioral amendments like practicing social distancing while being outdoors and avoiding touch and tactile contact have brought immense difficulties for people with visual disabilities. The impact involves difficulties faced while accessing healthcare facilities which can be curbed with more inclusive services and support from the caregivers, family members, or healthcare providers along with the strong support of the community which can help in the improvement of all the severe outcomes.

One of the important characteristics of people with visual disabilities is that they use their sense of touch to familiarise themselves with their surroundings. Visually impaired people use their hands to touch the objects and identify them which is against the health recommendations during the spread of COVID-19. Therefore, without any proper guidelines, people with visual impairments are exposed to the virus. For instance, the habit of touching the eyes or face incessantly can spread the virus and make them most vulnerable.

People with visual impairments heavily rely on support from others. Even during the times before the pandemic, access for visually impaired people was extremely poor. For instance, pedestrian pathways are poorly constructed for the cane users where they lack the guiding block. Such inaccessibility leads to an increase in dependence on other people. Having said that, the rules of physical distancing bring difficulties for visually impaired people in terms of accessing services because they look for a companion's arm while walking or crossing roads, and this very act requires them to be physically close to that person which goes against the norms of social distancing.

When the Government of India announced the very first phase of the lockdown, it recommended various new behavioral measures like stringent social distancing norms, staying at home, incessantly washing hands or wearing masks. Such emergency measures posed immense challenges for people with disabilities which already stood aggravated by the anxieties and threats caused by the outbreak. The adoption of new behavioral patterns like social distancing came with bigger limitations and difficulties for people with vision loss. Depending on others for their basic procurements and

personal assistance, people with vision loss face massive challenges at supporting their regular activities. People with visual disabilities tend to draw spatial representations of their environments in their minds which helps them to be a part of the surroundings. The inappropriate changes brought by the government measures in the environment to control the spread of COVID-19 are causing massive disruptions in the mental mapping done by people with visual disabilities. Moreover, people with visual impairments have now started feeling that they have become more dependent ever since the beginning of the lockdown. This feeling of dependency has taken a toll on their mental health. People with visual disabilities already tend to feel more lonely than other abled populations. With a stringent policy of being at home has caused depression and now they are more likely to face both mental and health problems resulting from self-isolation.

Limited access of people with visual disabilities is one of the biggest challenges. The government has completely ignored the situation of many visually impaired people who not only have visual disabilities but also low literacy skills. Many of them are unable to read because of no access to education. However, for those who have access to education, they need the information written in Braille or in any other manner which is accessible for visually impaired people. There are many NGOs who are coming up with initiatives that can provide a more accessible form of information for visually impaired people. However, such initiatives are still far-fetched and it is difficult to predict their success. Besides this, several other issues aggravate their problems. For instance, sitting at home and doing work online with a limited internet connection. They tend to face apprehensions like failing to be present during online classes or lectures at institutions or working online which makes it a very critical situation to be a part of distance learning. However, considering developing a disabled-friendly model of distance educational system can prove to be helpful.

4.4 Accessibility Failure of COVID-19 Infrastructure

It has been noticed that the government websites that carry information regarding COVID-19 cannot be accessed or read by visually disabled people as the content is projected on screen-reader software which is not disabled-friendly. For instance, the Arogya Setu application which was introduced by the Indian government to detect the people who are exposed to COVID-19 and mainly to share all the necessary information

regarding the spread, does not have a disabled-friendly software. Moreover, not only visually impaired but people who live under extreme poverty or students who reside in dormitories do not have the privilege of accessing televisions which in the end proves to be a disadvantage as it prevents them from receiving all the important information.

In India, there has been an increasing demand for isolation facilities and with the massive rise in the COVID-19 cases, health care spaces like general wards or day-care centres have been converted into isolation wards. However, within India, many isolation facilities are not disabled-friendly as many of them lack railings, ramps or toilets. The toilets are situated extremely far away from the isolation wards, and people with disabilities are not even assisted while taken for sanitation purposes. Moreover, the severe restrictions on movements during the pandemic has made it more difficult to build alternative isolation wards which are disabled friendly.

4.5 Breaking Barriers

Hospitals lack tactile pavements which make the visually impaired more dependent on others for help. The presence of signboards can be helpful in terms of assisting people with hearing impairments. For people with orthopedic disabilities, operational lifts must be available. There is a need to train more medical healthcare workers so that they are given the tasks of assisting people with disabilities during quarantine, treatment or while testing. It has been surveyed that disabled people in the isolation wards are left neglected and unanswered by the nurses and doctors which in the end impacts their mental and health situation and they tend to lose their lives while being in quarantine. The government, on the other hand, must plan and create an alternative support system providing helplines that would offer support staff and transport facilities to people with disabilities because currently there is a lack of a concrete structure for the betterment of the disabled during the pandemic. The government should implement WHO guidelines for the disabled in the hospitals and should impose them on the healthcare workers. These guidelines should be advertised and talked widely among the masses so that the abled people come forward and help the disabled.

A strong change in the support and economic structure for people with visual loss is undoubtedly required in this pandemic situation. A set of measures that ensures the

adequate and continuum of services, care and other important facilities during the COVID-19 pandemic is needed. Therefore, there is a need to develop a support system that is more practical and feasible in terms of assisting and reducing the fear and anxieties of people with disabilities in these difficult times. There is a serious requirement to ensure that people with disabilities are made accessible to every information related to COVID-19. When disabled people succumb to the virus, isolation wards should be situated near the toilets or to be attached in their isolated wards. Sensitive and trained health-workers should attend disabled patients whenever they are in need. Having said that, the information needs to be easily available in their accessible friendly formats. Healthcare buildings need to be more physically accessible for people having sensory, cognitive, and mobility impairments. Moreover, there is a need to ensure that people with disabilities do not have to face financial challenges while accessing health care services during emergencies. The pandemic seems to be only at its beginning, and the sooner the government and various institutions start giving a thought about including people with disabilities while making policies, it will be highly fruitful for the community. The people who are already marginalized in society should not feel more threatened during these hard times. According to Article 21 of the Indian Constitution, they too have a right to live. Apart from that, they too have the right to receive adequate information, health services, social services, and most importantly education related to the present times, and for that stringent policies should be made inclusive of people with disabilities criteria and must be followed nationwide.

To make sure that people with learning disabilities continue to get good quality education, the system requires stringent actions that can prioritize their needs for accessibility, adaptation and learning plans. Teachers need to be trained in developing content for students with a learning disability. With the online source of education, subtitling of the lectures, options for sign-languages and inclusion of remedial classes can be extremely helpful for those who have been excluded from home-based education programs and ensuring the fulfilment of their social and emotional needs. Therefore, recognizing the existing inequality, there is a need to call for stronger support from families, educators, health care systems and curriculum developers.

A much more encouraging approach has been witnessed where the universities and other organizations in the world are transitioning to the online mode of delivering lectures and other services in a manner that benefits everyone. Even in supermarkets, there is now priority grocery access dedicated to older or disabled people. In some areas, people are coming together and supporting each other in some manner by sharing words of kindness and offering help. Such measures are important to help everyone to get out of the pandemic crisis. However, such measures would be beneficial for disabled people even after the pandemic is over. People will be more accepting and kind towards them, and would not make them feel marginalized. Therefore, post pandemic, the abled people would continue to include people who live a relatively different life creating a more connected and a more considerate world that allows people with disabilities who live inside the margins to step out of isolation both physically and mentally.

5. CONFLICT OF INTEREST

The authors declare no conflict of interests.

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