

Making themselves heard: deaf people in India during the global COVID-19 pandemic

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The onset of the sudden and global pandemic, COVID-19, has forced all of us to change our ways of living and interacting with the outside world. Additionally, a lot of restrictions on movement mandated by governments have also been issued in the past few months. In the context of India, a nationwide lockdown was in place from mid-march till the end of May. These lock-downs have had serious consequences for various segments of the population across the country, especially, those on the margins, who are vulnerable and/or in a minority. One such segment has been the disabled population. This paper, with the help of narratives, addresses the challenges faced by the deaf population during the COVID crisis and the ways in which they have negotiated these. There has been a big void in the dissemination of information to the deaf, owing to the fact that the majority of information from official sources has not been translated into sign language. More so, in times when information is the key to maintaining proper health care, this is a big lacuna. Additionally, the paper will also talk about the role of technology as well as of deaf groups in the lives of deaf people, and how it has proved to be very helpful to not just spread proper awareness about the pandemic, but also in trying to build up a movement in trying to recognise Indian Sign Language as the 23rd Official Language of India.

Keywords: COVID-19, Deaf, India, Indian Sign Language, Government Policies

Introduction: COVID-19 and the situation in India

As defined by the World Health Organization, COVID-19 is an ‘infectious disease caused by a newly discovered coronavirus’ (World Health Organization, 2020). It was projected that most of the individuals who were, or would be infected with the virus would experience symptoms that would be mild to moderate in nature and most individuals would be able to make a full recovery without ever requiring any special treatment. However, those who were older in age and/or already had underlying medical conditions, such as heart disease, respiratory disease, cancer and such, would be at a higher risk of developing the disease and a more serious version of it. Since it spreads by contact through saliva or discharge from the nose of an infected person, it is important that everyone follows proper respiratory etiquettes (ibid, 2020)

This virus reached India as early as 30 January 2020 after a case was detected in the state of Kerala. These increased to 22 cases by 03 March 2020, and were reported from all over the country. Following this, the number of cases started to rise exponentially, with 50 cases being reported just seven days later on March 10, 2020. It was on March 25, 2020, almost two months after the first reported case, that a nationwide lockdown was announced which was to be in place till April 14. However, since the announcement came overnight, it led to a massive panic within the nation, especially among those whose primary source of livelihood had now been displaced. This group largely comprised migrant labourers and gave rise to one of the biggest internal migrations of people that the country had seen in recent years. Workers who were desperate to get home and were without any means of transport or other essential facilities, started to walk back to their villages and home-towns. The number of cases during the lockdown, however, showed an upward trend, and as a result, by the time the lockdown was to be lifted in mid-April, the cases reached almost 10,000. This prompted the government to extend the lockdown three times, from May 3 to May 17 and then till May 30, 2020, upon seeing the rising number of cases at each juncture. Finally, on June 08, the process of ‘unlocking’ the nation was initiated. The country remained in lockdown for 75 days, which was the longest for any country around the world (The Wire, 2020).

The pandemic now is a part of our lives and has brought new norms of living and a modified lifestyle, which includes social distancing and maintenance of ‘proper hygiene’. This ‘new’ lifestyle has brought into question the social, political as well as the health dimensions during the pandemic, and the paper specifically looks into the challenges faced by people with disabilities. Across the globe, a lot of organizations, activists and people with disabilities highlighted three major areas which were a major source of concern, namely medical ableism, the cost of living, and the importance of communication (Kuper et al., 2020). The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) is responsible for identifying and addressing the rights of persons with disabilities, and ensuring that they are guaranteed to them. One of the major problems that came up during the pandemic was the assumption that there was no need to put forth any special provisions for persons with disabilities, and assumed to be covered like the rest of the population (ibid, 2020).

This long spell of the lockdown affected numerous sections of Indian society, the disabled population being one that was negatively affected. A major reason for this is the fact that the government failed to register the extent of the impact that a lockdown would have on this segment of the population. Much of the advocacy that has been going on in the country with regards to COVID-19, mainly revolving around maintaining distance, did not consider the problems that might be faced by those who may be immobile or those who may need special assistance throughout the day. It showed a contrasting picture between what the roles of the state should have been; that is, reducing the effects of the crisis, against the actual role of the state in responding to the needs of India’s diverse population. Regional disparity, access to healthcare, and the underfunded and poorly managed health care system, all contributed to a

grim situation during and even after the lockdown for a large part of the population (Rahman, 2020). The presentation of the early reporting of the pandemic centered around the notion that the elderly and those with a previous existing medical condition were at high risk of the virus, while the young and the healthy were more or less safe from it and so, it wasn't such a big threat for the latter. Such narratives also portrayed an ableist notion whereby those with a non-normative body play a role in assuring the normality that the temporarily able bodies exhibit (Goggin & Ellis, 2020). However, ironically, ability as a construct, relies to a very large extent on the construction of disability, as there are no 'normal' bodies without having disabled bodies to be placed in opposition to them (Campbell, 2009).

Within the context of disabled bodies, it was contested that in a pandemic, people with disabilities will be heavily discriminated against. This was so, as a non-disabled person is sure to 'win' over the right to use essential resources, as they would have a better life expectancy and/or quality of life. Additionally, issues of social distancing and good hygiene, practices which all of us are expected to follow are not always feasible for a lot of people with disabilities. For people with intellectual impairments and for those belonging to the Deaf-Blind community, it is not always easy to maintain social distance. The former may require assistance in order to be able to go through their everyday affairs, while the latter often need touch to communicate (Goggin & Ellis, 2020). Apart from this, it also became vital that people be kept regularly updated with the latest news. In light of this, it became essential that this information be made accessible to people from all walks of life, which included persons with disabilities (Armitage & Nellums, 2020).

Moreover, in a country like India, historical social factors such as ignorance, poverty, a general lack of amenities, and fewer accessible amenities, have led to further marginalization of persons with disabilities (Bellamkonda, 2020). Even post-lockdown, the presence of a class divide, coupled with governmental negligence as well as inaccessibility to healthcare and employment opportunities is very clearly visible. Persons with disabilities along with their families find themselves trapped in a vicious circle where their social status affects their lack of accessibility to health care and services. Further, the presence of disability reduces their social status, making the aforementioned inaccessibility worse.

Many disability activists and groups contend that this is not new. The government has always treated persons with disabilities as an almost invisible group, and concerns about them comes as an afterthought, if at all. A lack of representation in the parliament further adds to their woes. People who are already at a high risk of infection now have to face the struggles of the virus head on, without any additional support (Suchitra, 2020). For example, a recent report published by Rising Flame and Sightsavers throws light on the issues faced by women with disabilities in the recent COVID pandemic. The report clearly lays out the multiple ways in which the people have had to face issues, which included issues of access, food and other essential items, social protection, education, employment, as well as health and hygiene. The

report also discusses how access to information, communication and to the digital world was also a challenge. The latter may not count as essential services but in today's evolving world, the complete reliance on the digital world makes it as essential a commodity as any other (Rising Flame and Sightsavers, 2020)

Background: Understanding the impact of COVID on the deaf population in India

With the emergence of COVID, newer understandings and ways of living have come about. Novel sources of information everyday made it very difficult to decide which source is to be believed. This holds true for the deaf and hard of hearing community too, as even though there was a multitude of information, there was hardly any source that was accessible and genuine. The sources of information that were circulating were usually not verified and were not from trusted sources such as the government or a major medical institution of the country. This led to a lot of confusion as to which information was true. Keeping this in mind, the World Health Organization uploaded a course titled 'Introduction to COVID-19' in a variety of languages, out of which one is ISL (Indian Sign Language). The translation of text to ISL has been done by interpreter Vinayachandran B S, a resident of Thiruvananthapuram. Given the fact that ISL is the primary language for a majority of the deaf population in India, this course was a welcome relief for the community. The Rehabilitation Council of India had also taken the initiative to encourage this course (The New Indian Express, 2020).

The actual situation of people on the ground was a little different. For the deaf population, while the pandemic came as suddenly and caught them unawares as any other member of the society, the lack of proper resources and adequate means of communication left them stranded. A lot of deaf individuals who are students are usually enrolled in deaf schools which have boarding facilities. At the onset of the lockdown, these children were asked to go back to their homes. However, at home, a lot of these students do not have access to sign language, and as a consequence, access to information about the ongoing situation was limited (Chandani, 2020).

Methodology

In order to better understand the situation of the deaf¹ community during the COVID situation, a questionnaire was prepared by the author and sent out to various deaf groups, organizations, and individuals to fill in the month of July. At this time, the country was in its 'unlock' process and all efforts were made to try and understand the situation of the respondents, both during as well as after the lockdown. Within the short span of time that these questionnaires were sent, ten responses were received. The questionnaires were posted on various social media groups that were known to include members of the deaf community. The questions were in the format of a Google form which was completely anonymous as it did not ask for any identifying features such as name and email address.

Within the form, it was ensured that if there was an opinion-based question, the respondents could select multiple ones as well as provide an answer that might have not been mentioned as an option. The usage of questions with options was made so as to give a slight structure and also to give a direction to the questions. Responses were received from participants within the age bracket of 15- 50 years, with five being in the 15-25 age category, four in the 26-35 age category while one in the 36-50 age category. Prior to the lockdown imposed in March across the country, four respondents were studying, five were working, and one was not working or studying. Of the ten respondents, one respondent identified as being deaf-blind, whose issues are a little varied from those of nine deaf only respondents.

Findings

Information about the lockdown

The suddenness of the announcement of the lockdown left many deaf individuals without any proper source of information. The lockdown speech as broadcasted by the Prime Minister was interpreted in Sign Language on Doordarshan News (the autonomous public service broadcaster founded by the Government of India). However, post-announcement, a lot of deaf persons complained that they were not able to understand the signing done by the interpreter. It was hoped that another interpreter would be hired, as such important announcements could not be miscommunicated. But, the interpreter was still not replaced. This made the whole exercise of having a sign language interpreter redundant (Chandani, 2020). Since the information on the national broadcast service was not considered to be reliable, the most popular outlet for information among the respondents was social media, which included sources like Facebook, Twitter and Instagram. These were selected by eight out of the ten respondents. Information gathered from WhatsApp was a close second, with it being selected by six out of ten respondents. Additionally, news channels which broadcast in ISL were also selected. The only exception was the deaf-blind respondent who got the information through family members. Here, it can be observed that while for the deaf respondents, absence of sign language sources proved to be a major hindrance to access information, for those with both hearing as well as visual disability, absolutely no provisions existed to convey the information to them.

During the lockdown, seven out of ten respondents said that they travelled from one state to another. This was due to the fact that a lot of individuals had to shift out of their hostels with all of them closing in light of the lockdown. Another reason for the travel were the parents and/or family members calling them back home, concerned about their health as well as of the fact that communication for them would be a major issue. Following the lockdown, all respondents stated that they did not travel, pointing to the fact that those who had travelled during the lockdown had still not returned to their place of work and/or study. However, travel

during the lockdown raises questions about the safety of the individuals who were forced to move from one place to another during the peak of a pandemic.

Information about COVID-19

Following the introduction of lockdown, it was also pertinent that people in the country be also educated about the nature of COVID - its symptoms, the precautions to be taken to prevent its spread, and what to do in case of contracting the virus. Among the respondents, while most knew of the major symptoms, a few claimed they did not have any knowledge about it. The lack of such a basic knowledge in a country where total number of cases so far is above 6 million, is not a good sign and surely needs to be investigated. The information of the symptoms also came from a variety of nonconventional sources like articles or videos on social media, or information from family or friends. None of the respondents chose newspaper as a medium of information, while only three chose television as one of their sources. This also points towards an increasing trend in the use of social media as a powerful source of information. Keeping this in mind, the governmental authorities should try to ensure that the information being presented is both reliable as well as accessible.

However, the issue does not end with the knowledge of the symptoms. One needs to go beyond this and tackle the next main steps of what happens when individuals exhibit COVID symptoms. All the respondents were of the opinion that if they were to experience symptoms, they would contact family members or friends. Two respondents in addition to this, said that they would contact the government helpline number as well. The preference for approaching a family member or a friend over other means can be easily understood, as they would be most comfortable with these people, but their reluctance to approach the government help lines could also be due to these services being provided only over the phone or via emails. A major concern for the deaf population is that they will not be able to place such calls without the assistance of others, nor are they fluent enough to write emails in either English or Hindi, owing to a lack of education in ISL (Chandani, 2020). Such gaps could lead to a situation where a section of society gets left behind in the attempt to fight this pandemic successfully.

The government has also not made any additional effort to provide the deaf population with details pertaining to COVID. Upon being asked if the information provided by the government is enough, two participants responded negatively and seven responded that they were not sure. This ambiguity might have emerged from them not knowing the complete information in the first place, and so they were unsure if they knew all the information or not. Interestingly, none of the respondents thought the information to be adequate and all felt that there was a lacuna of some sort. The reasons as to why they felt that the information was lacking, was attributed to the inability to access verified governmental sources that presented the information in sign language.

COVID and family life

As mentioned earlier, a lot of individuals had to move out of their temporary accommodations in the cities and move back in with their families. Nine respondents out of the ten were living with their families during the lockdown period, and of the total, half continued to work or study from home. All of them claimed to have had no problems in working/studying from a remote location. The digital platforms and new technologies, especially the popular use of video calling, has always proved to be a very useful feature for people who live with hearing impairments or are deaf. Deaf people have always greatly benefitted from the emergence of the new means of virtual communication (Gulyani, 2019) which was the case here as well. Communication with family and deaf friends was reported to have either remained the same, or in one or two cases, increased. This confirms the fact that with the help of technology, the respondents were able to maintain the usual lines of communications they had previously. During the course of this lockdown, the usual routine included helping family with the household chores, being on social media and/or communicating with other people on video call. Overall, the respondents felt that the lockdown was a bad move as it caused a lot of difficulties. One of the issues was that during this period, individuals were forced to take up low paying jobs to financially sustain their families as not many people were interested in giving them jobs in the prevailing situation. Another major concern that came to the fore was the fact that even buying essential commodities was a problem, as the police and government authorities did not know sign language. This made stepping out of the house very unsafe as they were not able to explain their reasons for the same. In the early stages of the lockdown, this was also noticed with regard to the boarding of trains and other transport services, and then later at quarantine centres where they were not able to convey their basic needs and answer as to whether or not they were feeling unwell (Business Insider, 2020).

Life post-lockdown in the pandemic

Since the past few months, masks have become an essential commodity in the fight to combat and lessen the spread of COVID-19. The Indian government is also levying fines and/or penalizing people for not complying with the order to wear a mask. These orders are leading to an increased sense of discomfort for people with speech and hearing impairments (Business Insider, 2020). For this group, especially for those who lip read as well as use sign language, it is a catch 22 situation. While masks are essential to stop the spread of the virus, their use also makes it difficult to communicate and understand other people. While those who lip read are totally cut off from everyday forms of communication, those who use sign language also rely to a very great extent on the use of facial expressions as part of ISL communication.

All respondents, except one, claimed that they were wearing masks whenever they had to step outside, but all respondents said that masks made it harder than before to be able to communicate. Most of the respondents have now stopped stepping out of their houses and are

relying significantly on their able-bodied relatives and friends for communication. However, there are also instances where individuals have come forward to look for a solution to this issue. A social project named 'Breathable Communicator Masks' started by a Delhi based entrepreneur was one such effort. The masks made by the organization had a see-through plastic patch, which would facilitate the communication to a great extent (The Hindu, 2020). It is yet to be seen whether these masks catch on and are being used successfully by the deaf and hard of hearing population.

Major challenges faced during COVID and the role of sign language

The issue of communication was a major problem in the lives of the deaf during this pandemic. The deaf are already at a disadvantageous position, where the language that they are most comfortable in, sign language, was not used as a mode of communication in the country. This further acts as an impediment in the course of their lives as they are unable to access healthcare, education, employment and so on, given the language barrier. Compounded by the lockdown, the situation became worse where they had to be completely dependent on others to access information and to communicate. And this communication is not just pertaining to their everyday life, but also in terms of communication with police and healthcare workers, who are at the frontline during these times. The lack of communication with these two groups adds to the woes as daily living becomes very difficult.

The lockdown also forced a lot of individuals to be with their families, who more often than not are not well versed in sign language, and so are hardly able to communicate with their deaf family member. This isolation from the group of people who are fluent in their means of communication may have adverse effects on the mental health of the individuals as well. Technology, no doubt has been of big importance in these times as it has helped them to still be aware of what was going on in the rest of the world, as most respondents were able to name at least some international incidents that had taken places in the last few months. Technology was also a great means to keep in touch with other members who are also deaf.

Loss of employment was also a source of concern, and a few respondents had to take up alternate lower paying jobs in order to support themselves and their families. Finally, physical distancing was not very feasible especially for the deaf-blind respondent who developed hearing loss later in life and uses a hearing aid. The physical distance then makes communication a problem as physical proximity is essential for the proper functioning of the hearing aid. Additionally, usage of masks, which is a mandatory practice, created more hurdles in communication.

Continued activism among the pandemic

At present, there are more than 18 million Indians who are deaf or hard of hearing. It is essential

that they have access to sign language from the very beginning so that they may have equal opportunities in life. In order to make sure that the deaf population is not left behind and can avail the benefits that are due to them, the National Association of the Deaf had started a campaign in 2019. The aim of the campaign was to create awareness among the deaf people, the educators, the ISL teachers as well as the interpreters around the issue of inclusion of Indian Sign Language into the Indian constitution and it being recognized as the 23rd official language of the country. The campaign hoped that it would reach lawmakers so that the importance of ISL in the lives of deaf individuals is prioritized politically (Newz Hook, 2019).

In the lockdown phase especially, efforts were put in place to make sure that awareness around this issue does not recede. A popular Bollywood star, Ranveer Singh, produced a music video which was entirely signed in ISL. The three-minute video shows a man signing while the song is also played in the background. The description of the song mentions how it is also an attempt to set into motion a conversation around ISL and the attempt to make it an Official Language in India. (Hindustan Times, 2020) The video was very popular among the deaf people and was widely shared and circulated. Its popularity can also be attributed to the fact that this was one of the first few official videos in India to have a sign language interpretation, and was produced and promoted by such a popular star. The lockdown added momentum to this, as the issues faced by the community were evident.

The respondents added that the recognition of sign language as an official language would be very beneficial as it would be an important bridge of communication, not just among deaf individuals, but also between the deaf and non-deaf. Making it official will ensure that all government communications, media outlets, and other government professionals, including health care workers, will either communicate in it themselves, or have the presence of an interpreter at all times.

Conclusion

The pandemic has been a trying time for all of us. The repercussions of this are still being seen and will continue to unravel in the time to come. But the onset of this phase has been more taxing for certain sections of the society. Coupled with pre-existing social, cultural and economic factors such as caste, class, gender, and disability meant that a lot of groups have already been at a disadvantageous position in the society, much before the onset of the pandemic. Employing an intersectional lens to understand these overlapping factors is complex yet essential. The paper has tried to look into the challenges faced by the deaf population both during the lockdown, as well as after it. Sign language and its role in communication emerges as a major need, more so in critical situations like these. And for this reason, there is an urgent need for the authorities to address the issues raised by the members of the deaf population, and recognize the importance of Sign Language in their lives. Subsequently, it is hoped that there will be the development of a strong network of information and communication systems and

an easy availability of interpreters. It is desired that basic sign language be known to all, important information be conveyed via sign language, to have help lines exclusively for deaf people and finally to recognize the language as an official language of India. The pandemic has exposed the shortcomings of the existing governmental policies and their implementation, and now more efforts need to be made to ensure that the stakeholders are a part of the policy making process.

Notes

¹ The terms deaf and Deaf signify two different meanings. While deaf refer to those who are medically diagnosed with a hearing loss, Deaf refers to those who in addition, consider themselves as a linguistic minority. For the present work, the term deaf will be used, as the article is trying to look at their issues from a point of view of their medical identity rather than specifically from their cultural one.

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