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Psychosocial Consequences of COVID-19 on Persons with Visual Impairments

Mahima Nayar[a*], Srilatha Juvva[b] and Chitra Lakshman[c]

[a]Psychiatric social worker and independent researcher; [b]School of Social Work, Tata Institute of Social Sciences, Mumbai, India; [c] Honorary Director at Vidya Vardhini Foundation Trust, Mumbai. Corresponding Author- Email: mahimanayar@gmail.com

The ongoing pandemic situation has disrupted lives globally. These disruptions are embodied in gender, social location, ethnicity and in the body. Public health facilities, accessibility of urban infrastructure, support services for persons with disability, educational accessibility in cities prior to the pandemic have influenced the manner in which disabled people are able to adapt to the current situation. This paper presents the experiences of young people living with visual impairments who reside in an urban low-income community in India. It explores the unique challenges such as the further reduction in accessibility to health and educational facilities that they are facing and the manner in which their carefully structured everyday lives have changed. The narratives also describe the manner in which they are coping with the public health disaster in addition to preparing for the new 'norms' that people living with visual impairments are required to navigate as an outcome of the pandemic. The paper gives voice to their needs and requirements in this situation, and in turn, aims to inform policy responses through first person accounts.

Keywords: Young people; COVID; lockdown; vulnerability; coping

Introduction

The unprecedented scale of the pandemic has caught many off-guard including governments, international health organizations, civil society as well as health workers. Everyone has struggled to cope and adapt to the 'new norms'. At the initial stage, people talked about the pandemic being an equalizer as it 'supposedly' impacted people equally– across nations, across class, caste, race, ethnicity. However, soon there was a realization that it is not an equalizer and its impact is disproportionate across different populations. People who have existing vulnerabilities are likely to face more hardships because of the existing pandemic. Vulnerability is dynamic, locally specific and manifested along social, gender and poverty lines. Vulnerability varies between individuals, households, communities and regions. This creates various kinds of inequalities (Kakota Nyariki et al., 2011). Vulnerability indicates a condition that limits the abilities of individuals, communities and regions to resist certain debilitating processes and improve their well-being (Taro and Tidsskrift, 2004). Therefore, postdisaster contexts often see systematic rights violations and amplify preexisting injustices for the poor and marginalized (Button and Schuller, 2016). Long standing structural issues such as the nature of a person's employment, housing, socio-economic status, region (urban, rural), gender, age, and disabilities determine the vulnerability of the person both to the coronavirus and the impacts of pandemic policy responses. Combined, these determine how a person can cope with COVID-19 and the situations unfolding around it.

Most studies highlight the challenges of containment, mitigation and control in informal settlements as there are many vulnerable groups who rely on informal livelihoods living there (Corburn et al., 2020; Mberu et al., 2014). The present containment policies, while important to combat the coronavirus and break the cycle of transmission, are likely to place many low-income households at the brink of hunger and starvation, a threat often worse than COVID-19, if not supported with necessary welfare measures. Cash and Patel (2020) argue that the lockdown strategy being adopted by countries in the global South may subvert the 'two core principles of global health: that context matters and that social justice and equity are paramount' (Lingam et al., 2020:174). The severity of the impacts of the pandemic on everyday lives are largely determined by access to basic necessities by poor households who are at the highest risk of the virus and the policies implemented by governments to contain it. The major concerns that are coming out of Covid-19 are the control measures taken to contain it.

These include quarantine, lockdowns, self-isolation, advice on 'working from home', travel bans, and the closure of schools, markets, places of worship and mass gatherings. Impacts that impinge on supportive capacities and networks have increased the existing vulnerabilities and produced new forms as the impacts lead to breakdowns in informal structures of social protection (Wilkinson, 2020).

For example, school closures in poor settlements increase household expenditure as children do not have access to meals (that are provided as part of early childhood education schemes in India) and may experience hunger and suffer detrimental nutritional effects.

The global disruptions are embodied, as can be seen, through the restrictions on the physical body and the norms of distancing as part of the government policy/strategy to control the spread of COVID-19. The everyday lives of people with impairments consist of negotiating with the restrictive structures (physical and attitudinal) which surround them. Many people living with impairments had achieved some kind of equilibrium with their environment. The pandemic has completely disrupted their carefully constructed pathways highlighting the need to understand their experiences of disequilibrium. Disabled people consist of a heterogenous group, and different kinds of disabilities pose different kinds of challenges. The age of the person with disability also has an impact on how the pandemic has affected them. One of the main groups which has been living in a low-income neighbourhood in the highly populated city of Mumbai is now facing additional vulnerability, especially among young people whose life plans have been disrupted. The lives of children and youth to date have been disrupted in multiple ways as efforts to contain the novel coronavirus required schools, childcare centres, colleges, recreation centres, libraries, entertainment centres, and many other venues to close down. Play is restricted in many ways and older children are physically separated from their friends and restricted from doing most of the social activities they enjoy, although social media offers some alternatives (Masten and Stefanidi, 2020). But access to social media is also determined by the number of resources a child/youth may have. In case this is restricted, their isolation can increase. It is children and youth, often, who are completely removed from the public eye (as parents may go back to work or go out for essentials). These were some of the reasons we decided to focus on the lives of young people and understand what they were going through. Most of the reviewed literature shows an overarching impact of COVID-19 on vulnerable populations. But the lived experiences of young people with disabilities during COVID-19, is not visible.

This paper therefore attempts to document the changes in the lives of young people living with visual impairments in a low- income neighbourhood in India.

Methodology

The study adopts a qualitative phenomenological approach, which aims to capture the lived experiences (Creswell, 2013) of people with visual impairments during COVID-19. It specifically explores the unique challenges they face in the living and learning domains of life; their strategies for coping with the pandemic and the new norms of highly restricted living with the lack of mobility; and ascertain their needs and requirements in this given situation. The third author (CL) heads an organisation that works with people with disabilities in an urban low-income neighbourhood. Through this service, we identified young adults with visual impairments and their parents using purposive sampling. The participants included, were a child or parent of a young child, who had any form of visual impairment, currently living together in the local low-income community for a period of 5 years (to be able to draw a comparison before and during lockdown) and have availed of the services of the NGO throughout this period.

Interviews were conducted with participants via telephone. The first contact was made by the third author (CL) as the representative of the organisation who explained to each of the participants the purpose of the study and the process. Once the participants had granted consent, the authors made initial contact with each of the participants giving detailed information about the research. An appointment was made for a mutually agreeable time. Participants were advised that interviews could last between 40-50 minutes. Permission for recording the interview was also provided, and participants assured anonymity by using pseudonyms and de-identified information throughout the reporting.

On the day of the interview, the purpose of data collection, informed consent and the assurance of confidentiality was reiterated. Interviews, using an unstructured interview guide, were conducted in Hindi and English. They were audio recorded and later the recording was transcribed. The narratives were used to analyse the data. At the first stage of coding, each of the authors transcribed the interviews and also identified the codes in their interviews. All authors read the narratives and further codes were identified. After several rounds of identification of codes, the main codes were identified and grouped into categories and themes.

Description of the neighbourhood

The nature of the neighbourhood – physical space and distance between the houses, availability of basic necessities and the kind of living conditions (sanitation, green spaces) have had a great impact on the manner in which people have been able to cope with the disaster. This makes it important to understand the neighbourhood from where data was collected for this study.

M-ward: Mumbai: The face of inequity

The data was collected from the site, Cheetah Camp, Trombay, located in the M East ward (neighborhood) of Mumbai, which has a human development index of 0.05, and where 77.5% people live in tenements (TISS, 2011). The M Ward was also ranked as performing the lowest in Mumbai's Human Development Report (2009). The ward houses displaced people from other locations from across Mumbai as they were dispossessed of their housing settlements into high rise buildings, forcing them to shift to M ward. This has created overcrowding and has had a significant impact on the little available infrastructure in the M ward. This impacted the infrastructure facilities by way of housing, water supply, public toilets, increased distances to health facilities and schools. During COVID-19, this led to inability to maintain physical distancing and a spike in COVID-19 positive people in the community. As a result, those with visual impairment and who depend on physical touch, faced greater challenges in managing their daily chores.

Located on the Northeast edge of Mumbai, the M Ward mostly comprises low-income, re-settled communities. Built in 1927, it is home to one of the largest dumping grounds in the country, with mountains of dry and wet waste from homes and factories of Mumbai. It is thus a major source of pollution leading to health hazards of people living in the surrounding areas. Despite infrastructural developments, such as a freeway, flyovers and monorail, the living conditions of the slum residents remain poor. Fifty percent of the population in M/E ward suffers from heart disease, diabetes, respiratory ailments, high blood pressure, tuberculosis; 45% of children have stunted growth and 35% are underweight. Cheetah Camp records 32% (highest) prevalence of diarrhea in children (TISS, 2011). The participants were chosen from the Cheetah Camp area of this neighbourhood.

Table 1: Details of the Participants

Name and Age of PWD	**Type of Disability**	**Education**	**Religion**	**Household Income**	**Type of household**	**No. people in household**
Kabir, 5 years *	Complete vision loss since birth	Montessori School	Islam	Rs 16,000 (before lockdown)	Rented (Rs 4000)	3
Sana, 11 years	Low vision since the age of 3 (associated mild intellectual disability)	Class V	Islam	Currently no income (Rs 10,000 before lockdown)	Own house (2 rooms)	6
Naina, 20 years	Low vision since birth	Pursuing Class XII (Arts) along with computer classes	Islam	Currently no income	One bedroom - Pucca House on ground floor (180 sq. feet)	6
Leena, 17 years	Low vision since birth	Pursuing HSC in commerce, along with computer classes	Islam	Currently no income	One bedroom - Pucca House on ground floor (180 sq. feet)	6

* For younger children, there is a need to conduct interviews using specific techniques which could not be carried out telephonically, and therefore interviews were conducted with one of the parents.

Results and analysis

To understand the impact of COVID-19 on persons living with vision impairment, we need to first understand their lives prior to it. All the four participants had worked hard to arrive at a certain routine and stability in order to organize their lives, to maintain a level of food and housing security, despite their situation of ongoing poverty as a person living with vision impairment.

Early history

All the participants in the study except for Sana had congenital visual impairment. Sana developed low vision around the time she was three years old. Both the two younger children in our sample Sana (11 years) and Kabir (5 years) were independent in activities of daily living (ADL) which included wearing clothes, bathing, brushing but required some assistance for their toilet needs. In Kabir's case, the family does not have a personal toilet and therefore uses a public one. Till now Kabir does his ablutions at a designated area in the home.

Naina (20 years) explained that she had challenges in ADL through childhood until early adolescence. Her mother used to bathe her and help her with all her personal care routine (bathing, dressing, her hair etc.) By 13 she became proficient in ADL including managing her menstrual hygiene. Leena, being the younger disabled sister in the family, became functional in ADL fairly quickly. However, for both of them, traveling or moving out of the house was restricted. Initially accompanied by their mother or sister, the two have learnt to travel together on the local trains, independent of other family members over the last year.

Everyday lives: Pre- COVID-19

The participants of the study had managed a certain level of independence and routine after several years of trial and error. Sana who is unable to read or write, found it hard to sustain herself in school. She was teased and did not have many friends in school. In response, a teacher came home twice a week to teach her and she was learning to read. This lack of friends got Sana dependent on T.V for most of her socialization and entertainment. Sana displayed behavioral issues at home including refusal to follow instructions. For Kabir, joining the Montessori school created a routine for him and his mother. Kabir was provided with meals at school and the teachers and caregivers were very supportive. He enjoyed his school immensely and made friends there. In the absence of his father (works in another city) school was a major source of socialization for Kabir and his mother. While at home, he spent most of the time indoors with his sister.

Naina's and Leena's routine included early morning prayers, exercises, breakfast and getting ready for their computer class which they had joined in November 2019. They were going to these classes for skill enhancement apart from their regular schooling. They had two hours of classes from 2 to 4.30 but left home by 12.30 p.m. to arrive on time. They had recently learnt to travel on their own with great difficulties and felt very proud of this achievement, which included changing trains at the station and travel in the special compartment for disabled persons:

> *Thoda sa difficult, actually kaafi hua* (it was a little difficult- actually it was very hard)…we would be confused about which train to catch/board from where, which platforms–adjusting to routines. Mummy had told us, but we had never travelled anywhere alone. Several times we reached the wrong places; we would leave early at 12.30 so that we would reach the class on time. Now we are more used to this and can travel without any major issues. We have been going since November; this has helped us to gain a lot of confidence. We picked up two things – computer skills and travelling alone in the last few months.

Naina's and Leena's days were packed after returning from computer classes; they attended an Arabic class, had dinner, spent some time on social media (WhatsApp) and spent some time with their family during the night. They were not allowed to go out with friends but often had outings to the beach, etc., with their family members. Naina has kidney problems and her father has heart issues, however, they avoided going to the doctor in order to save money.

Lockdown woes

Information about the new type of virus had been going around since January 2020, and the participants and their families read about it in the e-newspaper, on WhatsApp, television. But none of them were prepared for the extent of its impact on their everyday lives such as the sudden lockdown. They heard about lockdown from neighbours and learnt that there would be no trains or BEST buses to commute. This was shocking for them as public transport is considered the lifeline of Mumbai, especially the local railway network. This is the first time that there is a complete shutting down of the 'local trains' for such an extended period of time. Kabir's mother came to know about the exact situation through other parents in school. She explained to him about the 'illness in the city' which is forcing everyone to stay home and the importance of wearing masks:

> We never expected for things to happen like this suddenly. What was shocking – how will we manage? Shops would close down. We were anxious because we could not afford to buy bulk during lockdown.

Naina and Leena had a family discussion about their requirements for the next fortnight. In preparation, they bought vegetables and made decisions about the alternate ways of staying healthy. Their older sisters were designated the task of all outdoor purchases. Similarly, families of other participants also organized their necessities. However, after the organization of food and other necessities, arose the challenges related to organizing their days.

‘*Day and Night was the same’*

The advent of COVID–19 and the resulting lockdown threw all the routines in disarray. The participants and their families had worked hard to create a routine for themselves and become independent in implementing them. This sudden change appeared to quell their daily achievements. Besides other areas of their life, education too was impacted to a large extent.
Lack of individual attention in case of difficulties, unavailability of books, and high fees for private online classes, were some of the issues which increased the anxiety of participants. They felt that ‘*it is very difficult to learn during this time of social distancing.’*

> I take time in understanding the material so with lockdown how will I manage, with no books how will I get good marks? I don’t have words to describe the difficulties that I am facing. (Leena, 17 years)
> Classes stopped immediately and I was very disappointed, my course was ending in March and we had exams in April. I missed class teaching; our Sir would explain in person while we were practicing. I found it more difficult to understand the lessons on line. (Naina, 20 years)

These concerns about education reflected the feelings of other participants as well who required additional time for learning because of their impairments.

Facing losses: living with the ‘new norms’

Financial issues were at the forefront of the problems that the families were facing, ‘income sources dried up’. Aiyar (2020) describes the difficulties that people living in low income areas faced with regard to receiving care as well as access to resources. The earning members in all the families interviewed had lost their jobs. Getting together money for even essentials– medicines, nutritious food to build immunity, masks or sanitisers was difficult. Access to public toilets also became challenging, and Kabir’s mother who uses a public toilet explained that the charges were hiked from Rs.1 to Rs. 3, putting further pressure on families already on the brink of despair:

> Livelihood changes are the biggest, have difficulty with providing food for family, I also lost my father during the lockdown, there have been too many stressors and changes I used to manage my house earlier, but now I am not able to do anything for my family…have been at home since 4 months, don’t know how I have been managing. I can manage the ration, but we need other materials too for everyday living. At this point I have to close down my work. I have to wait for jewellery shops to open up for me to begin my work. (Sana’s father)

Kabir’s mother, who lost her own mother, also talked about the complicated process of

mourning during this period. Participants talked about buying and eating smaller quantities of food to ensure that scarce food items lasted longer. Although there were food distribution drives, not everyone was helped equally because of systemic issues or because of their own reluctance in accepting food rations. Sana's father said 'our MLA gives us rations.' However, Kabir's mother was denied the ration, as she was living on rent; whereas Naina and Leena's father was refused free rations and did not allow any of his family members to do so.
Another area of concern was related to everyone's health, all prior health issues became secondary, and participants reduced their medicine intake to save money:

> I am on a regular treatment for my kidney infection from Sion Hospital but I could not go to the Hospital for any follow up treatment. I was afraid of the COVID, also I came to know the hospitals can infect people and I was very afraid. I am managing with proper diet and not taking any medicines. I also cannot afford to buy any medicines as there is no income in the family after the lockdown. (Naina)

Naina and Leena also talked about not buying medicines regularly for their father who had heart problems. Fear, lack of money, and mobility restrictions were leading to reductions in accessing the health services required. This was true for Sana as well who had multiple health problems. The pandemic has reduced everyone's accessibility to healthcare. It has thrown hospitals and health care professionals into a liminal state between an individual and a community focus, between clinical and public health ethics, a juncture where historically marginalized communities are at risk of further disenfranchisement (Mukherjee, 2020).

Job losses and salary cuts were the result for many of the households. Extended families were the major source of support for the families who were left without an income. Parents, siblings helped out with the essentials but many of them were facing financial constraints as well. Therefore, participants talked about eating simple food and avoiding anything special.

Nisha and Leena's family were helped initially by the savings of their older sisters; rations were provided by their maternal grandparents and other financial help was given by their cousins. Accepting help from family came with its own difficulties. Leena often felt humiliated by the manner in which help was given. According to her:

> They really don't care! We have a one-bedroom house-it is in a bad state and it may break during the rains, but none of our relatives is willing to help us repair it. All these years our relatives did not give any help at all, only now they are helping because of fear (of god). I want to ask them - why didn't you think of this before? All these years they have never helped; even after my father fell ill and lost his job. It is only because they feel that God is angry that is why COVID-19 has come, and so they decided to help us. This is the reason I want to study well so that I am not dependent on anyone, I want to be self-reliant. I don't like receiving help from relatives.

COVID-19 and the resulting lockdowns have decreased the self-reliance of people, leading to feelings of low-self-esteem and sometimes even anger. Confusion is another emotion expressed by people, as during the initial phase they were not sure about what to do. Participants said that they did not receive any information or any further help from the local government bodies. For assistance that they required other sources of help including the NGOs/ trusts that were working in the area; ration, replacement and repair of visual aids, and so on were done with their help. One of the aspects of loss for people living with visual impairments has been to give up their hard-earned mobility and independence by confining themselves to the house. Sana's father explained how because of the fear of the illness, Sana's time outside the house had completely stopped and she had gone out only 4-5 times over the last four months. There are also constant reminders about washing hands and wearing a mask whenever she goes out. Leena also explained:

> My immune system is already weak, so I am very careful and take extra precautions, I avoid going out, but if I have to, then I always go out in Burkha, maintain social distancing and once I come back, my mother washes the Burkha properly.

In preparation for the future, Leena also talked about precautions she may take as she starts moving out of the house. These include firstly, not going out at all, but if forced to travel then she would take all precautions like maintaining social distancing, using sanitizer (though they can't afford it), washing hands and following basic instructions.

Lockdown learnings: new skills and coping

The advent of covid-19 has introduced a whole new set of conditions for living. While it started in high-rise buildings, its consequences are palpably observed amongst people residing in low income areas, where there is overcrowding and lack of space; which actually complicates ways of living and navigating life. All the participants described the various ways in which they were adapting to it. Online schooling, practicing on their own, learning new skills, spending more time with family, were some of the ways in which they were managing. Creating a new routine for themselves, learning new skills and figuring out different ways of keeping in touch with friends and family were some of changes that participants included in their routines. Naina and Leena talked about using digital media to keep in touch with friends, they also used the same to ensure that they were updated about current affairs.

In terms of taking on new responsibilities at home, they leveraged the lockdown to learn age-appropriate skills related to household chores. These included cleaning the house, hanging clothes, learning basic cooking (making tea, coffee), frying, cutting and chopping vegetables. This is an indication of coherence, which the ability to discern the situation and make good use of the available resources (Eriksson, 2016: 93).

Apart from household skills, Naina and Leena also volunteered for a weekly meeting organized by an NGO. This consisted of a group of 20 members wherein the group leaders prepared material on soft skills, business skills, how to search the internet and provided training for others. This also helped with developing leadership skills:

> I feel very good taking on the leadership- I always wanted to be a monitor or head girl but never got the chance, teachers used to tell me- how will you manage- and I always used to think- *give me a chance.* Because of COVID-19, I am thankful that I got an opportunity to guide people and be a team leader. (Leena)

Learning new skills, helped the participants to establish a new routine and also helped in reducing their anxieties. There were many issues because of which, they spoke about feeling anxious:

> I learnt that I have to be tough to deal with the COVID situation. I am also very anxious about the school and I feel that this year there will be no regular school, also how will I deal with the fees. I have to deal with financial instability as my husband has not started working as yet. (Kabir's mother)

> I became anxious about the computer course which could not be completed. My sisters losing their jobs, was very difficult to accept. I would become nervous at times and morning prayers would help. I also learnt that life can be made simple by keeping our needs less. (Naina)

Other ways of coping were related to gathering more information about Covid- 19 and learning to live with it and praying. Spirituality was one major way of coping for the participants:

> I feel that prayers work, they work slowly, but they help. Whatever we need, it comes to us. The other day I read about an actor who had to sell his car to buy essential items like food and I feel grateful that we did not have to sell household items. I immediately read *namaaz* to thank god.

One of the major things that helped people to cope was the support of their families. This was reiterated by Leena and Naina who spoke about great support from their sisters and parents:

> On one level, life after COVID has become very hard and depressing but on other level we have been able to understand each other better. I used to think I have the biggest problems, now I know Dad often does not take medicines to save money, mother manages finances in a wonderful manner. Sisters are also struggling, everyone is struggling, low vision is not the only problem in life. (Leena)

While talking about some of the anxieties and coping with things post-pandemic, the latent anxieties and questions came up for Leena wherein she brought up issues related to taunting, discrimination by family members because they were all girls as well as pressure to get married imposed on her elder sisters. When the sisters had a routine outside the house, many of these issues were not prominent, but it appears that during the lockdown period when everyone was confined to their homes, these issues became important again. Coping with COVID-19 related lockdowns, was not just about dealing with the new issues that arose, they also included the re-emergence of previous conflicts and anxieties.

Discussion and Conclusion

From the narratives it is evident that families that were surviving precariously have been pushed further into poverty following the lockdown. Challenges related to food, health, education, loss of skills figured prominently. Aiyar (2020) reported that the government ration did not find its way to the slum communities. Therefore, food insecurity was one of the major challenges that the families faced as is evident from the manner in which they have reduced their food consumption. The frequent mentioning of food – lack, and the manner in which they were getting it, implies that it was a constant concern for all. Another major area was health which was compromised during this period as participants and their families avoided health care settings because of fear of COVID-19 and to save money. In the face of a pandemic such as COVID-19, groups systematically disadvantaged confront the virus with stronger intensity (Bailey et al., 2017). This increases their vulnerability to the disease. Since this paper is about young people, education and loss of privileges, regularly came up. Schools and other educational institutions represented a social circle, food as well as a certain independence which was all lost with the pandemic. Increased anxiety, discrimination, disappointment and anger were some of the feelings that came up in the narratives.

In spite of the challenges, the participants were able to discuss some strengths that they had acquired during the challenging times. Ability to restart some routines through gaining independence in household tasks, working on studies while being at home, gaining new skills and an appreciation for family members and bonding helped in regaining confidence and decreasing their anxieties.

The participants also felt that there was a greater need for help from the government as all the welfare programs did not consider the needs of people with impairments. The information provided was limited and not always accessible. This increased confusion and anxiety amongst participants. The paper highlights the manner in which intersectionality of low income, lack of food, lack of social support, disabling environments and impairment impacted the lives of young people with visual impairments. It is important to recognize that people show resilience and move forward because there are no other options, and in spite of vulnerabilities, they carry on.

Despite people's resilience, lack of inclusive disaster/emergency policies or its implementation, exclude people with impairments. As first rights holders, they need to be consulted in the formulation and implementation of policies to ensure that their needs are considered. Resilience of people has to be enhanced not just as individuals, but also at the societal level to ensure the larger well-being. This situation of shared adversity needs collective action and institutions of governance need to actively ensure this collective resilience.

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