LIVING IN THE MARGINS: DISABILITY AND THE PANDEMIC

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ABSTRACT

Persons with disabilities often live in the margins, being excluded by the system as well by the impairments they experience. A pandemic such as COVID-19, further pushes them into invisibility, unless active attempts are made to consider them as entitled to the same care as others. This paper explores the manner in which pandemic pushes people with disabilities further into the margins, thus experiencing exclusion. The changes that the pandemic has brought in comes with a price that all people have to pay, However the social and economic costs that people with disabilities experience are uniquely different. The article focuses on economic and social marginalisation that ensues the pandemic and the state response and the struggles that PWD had to experience. Further this is compounded by social exclusion and 'othering' that not only complicates their life, but also worsens stigmatising practices. The paper discusses the interplay of the macro context, the market and life within the home that has altered during the pandemic.

Keywords: Disability, Pandemic, Peripheralization.

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INTRODUCTION

The lives and livelihoods of people have been severely impacted by the spread of COVID-19 across the world. In a world that is highly globalized and interconnected, this has translated into a state of unparalleled economic recession (Ozili and Arun 2020). In the South Asian region, COVID-19 has posed unique challenges to their economies due to the region's large population and high rates of poverty, deplorable health infrastructures, poor socio-economic conditions, inadequate social protection systems, limited access to water and sanitation facilities and inadequate living space arrangements (Rasul 2020; Hossain et al. 2020). The impact of COVID-19 on the social and economic lives of people has been severe. For people, who are already vulnerable and marginalized the impact of COVID-19 has been like a double whammy.

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One such group which has always existed on the ‘margins’ consists of people with disabilities whose social and economic lives have been disrupted because of the pandemic. Marginalisation describes both a process, and a condition, that prevents individuals or groups from full participation in social, economic and political life. People can be marginalised due to multiple factors; sexual orientation, gender, geography, ethnicity, religion, displacement, conflict or disability. Poverty is both a consequence and a cause of being marginalised. Thus, marginalisation takes many forms, occurs at different levels, may be situated within time and place and may become part of the lived experience of the individual if internalised. Further, it can only be fully understood when account is taken of the subjective and emotional aspects of human life and the interpretative framework of the individual (Mowat 2015). Disability marginalises in multiple ways. It may be the experience of marginalisation by the individual and recognised by the individual and others; marginalisation experienced by the individual but not recognised by others; individual is seen as marginalised, but it’s not recognised by the individual and finally marginalisation experienced by the individual and yet denied by the individual (Messiou 2012).

The ICF model of disability postulates an interaction between the person’s health condition, the environment and personal contexts of these individuals (CDC n.d). McDougall, Wright and Rosenbaum (2010) have proposed an ICF model of disability and functioning that focusses on the outcomes of the person’s quality of life and his/her potential for development that arise from the interconnected, ever-changing influences of health, functioning and contextual factors’. This has a direct relationship with the larger social and economic contexts at the macro level and the ways in which they impinge on the person living with impairments or disabilities (ibid). Thus, a systems view is adopted to understand disability and the contexts which either accentuate or mitigate it. In this paper, we use the concepts of exclusion, marginalization and peripheralization to understand how socio-spatial inequalities that exist in the urban context increased the socio-economic distress for the disabled. Peripheralization ‘captures how economic, political and social processes invisibilize certain groups. It also highlights spatial type or geography, in this context the urban slum, the fringe of the city (Kuhn 2014). The micro-lens is focused on individual experiences of the disabled living in one slum and temporally located in the covid first and second wave in India.

As compared to disabled persons living in the higher income countries, those living in the low- and middle-income countries (LMIC) are likely to face more challenging circumstances.

People with disabilities in low- and middle-income countries (LMICs) are likely to experience the same financial and economic impacts as people without disabilities, but they are at risk of experiencing more severe and long-term impacts due to the exacerbation of pre-existing socio-economic exclusion during the pandemic (Meaney-Davis 2020). Within the margins, they are peripheralized and as peripheralization becomes a norm they eventually are excluded. Poverty and disability have many intersectionalities of gender, caste, religion etc., which lead to diverse pathways of exclusion, marginalization and peripheralization which needs to be understood to explicate the impact and to evolve inclusive processes.

People with disabilities in LMICs were already more likely to be living in poverty than people without disabilities, more likely to be unemployed, and if they were employed, they were more likely to be working in the informal sector, self-employed and in low-wage work (UNDESA 2019). Research prior to the pandemic showed that social protection coverage of people with disabilities in many LMICs was very limited and often insufficient to cover the extra costs of people with disabilities (UNDESA 2019; Kidd et al. 2019). Current evidence from April to June 2020 shows that many people with disabilities are now experiencing the same barriers to accessing social protection as prior to the pandemic, but these are exacerbated by restrictions on movement and the significant increase in demand for social assistance. The most commonly referenced barriers (marginalisation) to social protection include inaccessible communications (peripheralization) about social protection schemes, physically inaccessible or unsafe collection points, barriers to registration (eventual exclusion), and ineligibility for support in addition to disability benefits (Meaney-Davis 2020). COVID- 19 restrictions are leading to many long-term negative social and economic impacts on people living with disabilities. The marginalization of people living with disabilities is compounded by the fact that many social protection programmes introduced during the pandemic have failed to take into account their needs. The Minority Rights Group International has reported that the COVID-19 cash transfer programme provided by the Ministry of Social Justice and Empowerment in India and relief packages provided by local government in Nepal have excluded peoples with disabilities from marginalised groups such as single, poor, Indigenous women and women with severe disabilities. The packages are inaccessible to many who are unable to get a certificate proving their disability (ibid). These examples show how the disabled are being excluded from the programmes and having been finding it difficult to access mainstream anti-poverty programmes which will not reach them unless the discrimination they face is also addressed.

Mobility restrictions related to the concept of social distancing also have different repercussions for different social groups. For people from middle to higher income groups with the ability to 'work from home,' access to internet services and being able to use technology effectively, the confinement to homes was challenging but often did not lead to a crisis in their everyday lives. COVID burden contributed to increasing Disability Adjusted Life Years (DALYs) and the cost of productivity lost (CPL) to people in general (John et al. 2021) and can be safely assumed that it has worsened the situation for persons with disability. However, for people who were employed largely in the informal labour market the ability to maintain basic necessities of life also became difficult. It is in this context that the authors wished to understand the manner in which the lives of persons with disabilities were being marginalised and peripheralized during the pandemic using the qualitative paradigm.

Methodology

The data for this paper has been drawn from a larger exploration of the consequences of COVID on lives of persons with disability, across the two waves of COVID in one urban slum in India. The objectives of the study were to - (i) explore consequences of COVID on the social lives of persons with disabilities, with specific reference to adjustments and changed relationships with family and friends, and (ii) to understand the expenses and the losses with regard to their finances due to COVID-19 faced by persons with disabilities. We had to resort to telephonic interviews due the severity of spread of COVID and lack of safety for a face-to-face interviewing, during the lockdown period. The data was collected telephonically from the participants with prior consent. One call of 20 minutes was spent on introducing the researchers and the research topic and an appointment was sought for a detailed interview. The detailed interview, using probes from an in-depth interview guide, occurred over one or two calls ranging from 45-60 minutes, each. Due to the lockdown situation, we were able to obtain information pertaining to social and economic costs of COVID from four participants. Though we contacted other potential participants for the same, we did not get their consent for participation related to social and economic costs. There were several challenges that we faced during data collection. Since the data was collected at a time when there were movement restrictions, the interviews had to be done telephonically. This is also created some limitations in conducting the study. All the participants of the study stayed in on or two room accommodation. The movement restrictions consequent to the lockdown resulted in all the family members being at home most of the time. A few people refused to participate in the study because of lack of privacy in sharing information and the above reasons. During the second wave, many people faced health issues arising out of long COVID, many of them lost close friends and family members. These factors impacted the number of people we could interview in detail.

Data was collected from four participants who consented to participate in the study. Kumar[1] (male, 45 years) and Santosh (male, 39 years) had locomotor impairments and both used prosthetic aids. Shaaz (male, 5 years) and Sameera (female, 11 years), had a vision impairment, and their parents were included in the sample. The coding was undertaken by the first two authors independently and then codes and themes were compared. Using thematic analysis of qualitative data, the following broad themes were arrived at by collapsing the codes that were identified. The themes were used to locate exclusion, marginalization and peripheralization experienced by the participants to understand the multidimensional experience of hardships during covid. The participants hailed from a nuclear or an extended family set up in a low-income neighbourhood. They or parents of the children typically engaged in daily wage work or ran a small business that barely sustained their families.

Strained Realities

Living in low-income communities came with associated space constraints. Being confined in small spaces, often two small-sized rooms through the lockdown with little opportunities and scope for physical isolation had a toll on the adjustments that family members had to make. To compound this, online classes for children crammed the space further as Kumar’s family would have to complete all household chores before his son’s school lessons began. In the case of Sameera’s family, the father would work from home and thus would be able to keep a watch on his children including the eleven-year-old Sameera, while his wife and mother were engaged in household chores. Along with coping with the pandemic and the demands of the household, Shaaz’s family had to use the public toilet, the user fee of which was hiked thrice; and this was a strain on the family finances. Further, his mother had to work with him, as he had difficulty

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[1] Names of all participants have been changed.

adjusting to online classes initially, but gradually he was able to connect with his classmates and this routine had a calming effect on him.

In the case of Santosh, his wife and mother had to cope with the demands of pregnancy and birth of the child during the covid period. This meant increased expenditure for private health care as well as for travel by autorickshaws as public transport was curtailed. Kumar lived in a tenement that bordered a sewerage gutter and during the monsoon season of the year as the Covid, the gutter got clogged and dirty water flowed into their house. These are also some of the perils of living in low-income settlements which are often not well-planned. The pandemic has resulted in a reduced workforce in government offices leading to delays in addressing complaints. In the meantime, his children had to be sent to his sister's place till this issue was resolved. The everyday lives of people were thus disrupted directly or indirectly because of COVID. It required multiple visits to the municipality by Kumar to resolve something that is usually a part of usual monsoon maintenance. Thus, the peripheralization from regular government services and the resultant hardships compounded the impact of covid for them.

Participants experienced both the social and financial impact of covid and related lockdown almost simultaneously. There was an urgent need to stock up food and this was associated with having to spend whatever money they had on procuring the food. Though Santosh had money and savings he could dip into, having to wait in long queues with his polio-impaired leg posed a severe problem. While this seemed to be the entry point to the covid situation, the additional constraints of being unable to physically go to the location of material distribution and supply also posed a challenge to the participants. By and large participants 'had to' depend on friends and neighbours for assistance to fetch supplies that were offered. In many ways, their 'specific' needs were not factored in the process. He had to depend on neighbours for information about food distribution. Kumar had to request his young teenage son to, "*hold him up to reach the place…..my wife and my young son had to carry the material back. I felt awkward that I could not help them. The ration distribution was not inclusive - it was difficult for people with disabilities to reach the place for distribution…and I was uncomfortable as I had to ask others for favours*". Typically, there would be at least one starting point in such pandemic situations that an individual would be able to navigate. However, for persons with disabilities from low-income communities, it really seemed like a predicament that suddenly descended on them. This gap and juggle between the ground reality and what would have been ideal was too much for Kumar to fathom without support. The deficient efforts of the state's response to covid, the subsequent failure to factor the needs of the disabled, explicates the marginal lens of the state with respect to the disabled. For persons with disabilities, this seems to be one of the first points of difficulty to navigate, simply because of inaccessible environments. The pandemic also led to a setback on all the efforts that they had made to be independent and self-reliant. This was especially true for the younger people in the sample. The learnt skills related to self-reliance which they picked up in educational settings reduced as schools have remained online for most of the two years. While seemingly everyone has been affected by this crisis, those with impairments had their home situations and their relationships impacted more. On the one hand, persons living with disabilities shared many of the same worries as the rest of society. On the other hand, areas that affected them more (e.g., food and medicine) relate to the need for assistance and threats to resource access that has been brought to the fore in the current crisis (Dobransky and Hargittai 2020: 49). The next few sections discuss these factors more in detail.

Financial Costs of the Pandemic

Living with a disability during the pandemic was not only posing restrictions in everyday movement and constraints in interacting with others, but it also came with an economic cost as it meant, that persons with disabilities had to cope with increased costs in matters related to travel, and associated burden that they and their families faced. Broadly the occupation and family finances that were fluctuating due to the consequences of Covid affected pre-covid routines. This compounded the economic costs due to covid as has been extensively documented (John et al. 2021; Rasul 2020; Rasul et al. 2021).

Occupational losses and decrease in family finances resulted due to work of the breadwinners and persons of disabilities being affected. Shaaz's father lost his job and this affected his ability to support the family for everyday needs. As mentioned earlier, Kumar and Santosh were daily wage workers, whose work was disrupted due to the pandemic. Santosh used to design and stitch school bags. With the demand for school bags declining due to the lockdown, bags were not sold and he had to deal not only with the existing stock, but could not make new ones as there was no sale. He had hired a shop and they were doing well till Covid and its consequent lockdown set in. He had to give up his shop and work from home.

According to Meaney-Davis (2020), there is a lot of evidence to show that COVID-19 has led to loss of jobs and income for people with disabilities in low- and middle-income countries. This is especially true for people working in the informal sector. Our findings add to these observations as can be seen in the case of Kumar as well. Kumar would embroider saris and after covid, the demand for work came down and this affected his family’s income. To offset this, his wife and mother would make ready-to-eat breakfast at home and sell it. While selling this was easy during pre-covid times, during the pandemic they counted a lot on regular customers to sustain their business. His family was partly sustained by the sale of ready-to-eat breakfast to regular customers who ensure the steady supply of money to contribute to the family’s finances. However, after the advent of the pandemic, this was vastly affected due to the loss of customers and the inability to sell the breakfast. He reported, “*After the pandemic, customers stopped coming...and we suffered economic loss*”. Therefore, dependence on others much to the dislike and regret of persons with disabilities was enforced due to the pandemic. This is also indicative of a lack of accessible and inclusive response strategies during a disaster or epidemic. The economic dependence on siblings of the married couple compounded the sense of dependence as this seemed to be heightened due to the impairment.

It was only during the second wave of the pandemic that the business picked up, alongside he was able to pursue his work, “*I would work on the sewing machine and carried my own food and water as a precaution. Out of the initial seven only four of them were working now...many people lost their jobs*”. He was aware that if not for this work, he would have to engage in manual work with the municipality on a daily wage basis, and “*this is very difficult for me*”. Not only were jobs difficult to find, but they did not suit the needs of persons with disabilities, thus pushing them further to the margins.

The pandemic brought with it mounting family expenses, with little or nil income and increasing costs of living, both because of the pandemic as well as costs due to online classes and rising bills. The increasing costs also pertained to health issues that family members faced. For example, Santosh had to pay more for private health check-ups for his pregnant wife and feared that she would get infected if she went to the public hospital. The expenses were related to hospital visits, investigations as well transport to the health facility. This was corroborated by the experiences of Sameera and her brother, who had to make multiple visits to the hospitals for her frequent bouts of illness related to her disability and this meant depleting the family’s savings.

Santosh's wife delivered a child during the pandemic and while it meant frequent hospital visits, it also indicated more expenditure as the family expanded. As stated above, the state's services during covid, fell short of supporting most people in these difficult times, but these were woefully deficient for the disabled. This double impact brings the marginal position of the disabled which peripheralizes them on a daily basis.

Before Covid, the family had learnt to maintain their finances in a fine balance, as there was parity between income and expenditure, while saving for a rainy day. However, the savings were dipped into during the initial phase of the pandemic. Santosh and Sameera's family managed to save money which they subsequently spent. The pandemic threw their life out of balance and Santosh had to curtail his expenditure especially with the ill health of his wife and the birth of the child after covid; "*there is always unexpected expenditure with a newborn in the house*". This predicament is compounded by the fact that the state support in terms of relief materials is not only inadequate but also inaccessible for a person with a disability.

Adjusting To Changed Relationships

Changes in financial situation of the family reveal only one part of the narrative. The other consists of alterations in relationships. Terminologies which have become a part of our everyday usage like lockdowns, social distancing, masking, sanitizing hide behind them altered social/interpersonal relationships. Expressions of affection and concern within the family have been altered. For example, Santosh expressed his discontent about not being expressive with his son due to social distancing regulations due to covid. He said, "*I would be distressed due to safety norms that we had to follow because of the pandemic…I could not hug my four-year-old son, who would come running to me when I returned home…I had to wait till I had a bath*". The young son would feel very sad when his father avoided hugging him or picking him up. Santosh was also forced to "*avoid picking up my new-born baby, even though I desperately wanted to, as I was scared of passing on any infection to the baby*". Family members had to be constantly mindful about physical distancing to avoid getting infected. This was particularly in the case of the participants or the families who had to step out of the house on work. Children were discouraged from stepping out of the house and they were dissuaded from meeting their friends. This led to children getting increased time with the television as a way of getting them distracted and prolonged exposure to the television had its own consequences.

Besides difficulties in expressing emotions with children, the pandemic affected family members from being in regular touch. For example, Shaaz's 36-year-old mother lived with her in one city, while her husband lived in another city. Due to the sudden lockdown, he lost his job and he could neither send them money nor be with his family. Therefore, the family had to manage on their own. This necessitated the family to seek support from siblings to cope with the demands of the situation. Rukhsana, Shaaz's mother said, "*I had requested my brothers to help me with the household expenses and they supported me to tide over the most difficult phase*". The family continued to battle with loss of income all through the pandemic period.

Families altered their routines to suit the needs of their young members. This largely pertained to the studies of children. While Kumar's family completed their household chores, including the ones that fetched them an income well before the son's online classes began, Rukhsana prioritized Shaaz's classes over her daily work. She ensured that a routine was established for Shaaz to adjust to. This way, she not only enabled his adjustment to online classes, but also helped him cope with not having friends around him in the neighbourhood by actively engaging him in play. Due to work from home, Santosh shifted his computer and printer from the designer workshop in the neighbourhood to his house, so that he can supervise the studies of his children. This worked out well for him, as this meant that he did not have to go out of his home and be at risk of contracting the infection. At the same time, he could also work on his computer to innovate school bag designs.

Friends and neighbours who the participants would meet on a daily or regular basis were curtailed to only need based interactions during covid. During the first wave of covid, face to face interactions were almost absent with friends and neighbours. However, during the second wave, this had improved; even though it had not reached the pre-covid levels. Nevertheless, the participants reported that they and their friends have been in telephonic contact all through the covid period. They were thankful for their friends and for slashed phone rates. Kumar said, "*I am not used to talking a lot on the phone, but I would connect with my friends at least once a day, for a short call. Thank God that mobile data packages had come down in price and made it affordable to connect during such times*". Sometimes they would interact with friends to seek favours related to the relief material distribution and they were forced to do so. They did not want to be seen as need based interactions only.

Families have had to adapt to the changing times, altering routines within its household to accommodate the larger changes in the macro contexts outside. Disabilities and impairments only compounded the restrictions that the person and the family had to face. Due to norms of social distancing during the pandemic, movement was restricted, despite the patriarchal structure and functioning of the family. They needed assistance in procuring relief material. They were not informed in advance about such distribution thus lack of information puts them at a disadvantage in terms of being left out of such crucial matters.

Living In the Pandemic Times

Participants reported that the pandemic had taught them a few lessons. They learnt to grow with the pandemic and almost accept it as a way of life, while negotiating the processes associated with coping with it. For example, Kumar shared that he was learning to live with constant anxiety as we "*cannot fear as we have to face life as it is*". The reality of a new way of living seems to be more of the current norm than the fact that we will resume pre-covid ways of functioning. Santosh was most stricken by the severe financial crunch and for him the takeaway lesson from the pandemic was that, "*I need to save adequately to tide over any disaster, as this seems to the reality*". Parents of children with disability were preoccupied with resuming routines for the children, so that they stay connected in their lives. This is also in keeping with the realities of children with disability for whom a consistent and safe environment is essential for gaining basic life skills. Disruptions in everyday life create further difficulties for children with disabilities who are often relegated to the 'margins'.

CONCLUSION

The aim of this paper was to bring out the manner in which people living with disabilities have been further pushed into the margins because of the pandemic. They were already existing on the periphery and therefore with the advent of COVID-19 their vulnerability increased. Each participant in the study elucidates the experience of exclusion, marginalization and peripheralization at different levels of their daily life. Though the three concepts have a number of overlaps, all play a pivotal role in understanding the experience of inequalities and disadvantages from a people-based, impairment-centric and place-based lens. Thus, we can see disability experienced as a person, in relation to activities, to space and finally the multiple negotiations made in the space. This micro and macro lens captures the exclusion of the disabled from the dominant narratives of covid, marginalisation from spaces such as vaccination and peripheralized from options devised to deal with covid. Thus, all three together help elucidate "the effects of the state inscribed into urban space" (Wacquant 2008: 284), squarely focussing on structural processes that continue to impact the disabled persons.

In spite of the structural difficulties, narratives of the disabled persons show that they were able to sustain and survive in the periphery through their social capital. Fisher and Tronto (1990, c.f Dowling 2021) defined caring as "everything that we do to maintain, continue and repair our 'world' so that we can live in it as well as possible. It is through these caring processes wherein they cared for others and others cared for them (Social Capital) that surviving through the pandemic was possible. Friends, neighbours and family members helped them during the pandemic times in spite of being in challenging situations themselves. It is their kinship, friendship and community networks embedded within their everyday lives (Dowling 2021) that enabled them to maintain their lives and livelihoods.

However, this meant a very poor quality of life as scarce resources were shared. This makes it important for the State to step in and ensure that the rights of disabled persons are protected. Living during pandemic times is making it clear that unless governments ensure that there are adequate social protection policies which ensure an equitable environment; future disasters would push the people living in the margins into oblivion.

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