ORIGINAL ARTICLE



"We'll starve to death": The consequences of COVID-19 over the lives of poor people with disabilities in rural Nepal

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Abstract

There is no doubt that the sudden outbreak of COVID-19 negatively impacted billions of people worldwide, and among them, people with disabilities became most susceptible. However, little is known about the impact of COVID-19 on the lives of people with disabilities in Nepal. Using empirical data from semi-structured in-depth interviews with people with disabilities, disability specialist, and community leaders, this study discusses the lived experiences of people with disabilities who have been affected by COVID-19 in Nepal. This study revealed that the outbreak of COVID-19 impacted people with disabilities by worsening their vulnerability. In particular, the majority of people with disabilities became further isolated, were disconnected from existing services such as access to information, education, and health care and many lost their income opportunities. Findings from this study further show that this pandemic affected the rights of people with disabilities guided by the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). Immediate financial and non-financial support for people with disabilities from government and other stakeholders, such as non-governmental organizations (NGOs), is needed, indicating the need for policymakers to reassess policies to ensure that they adequately protect the rights of people with disabilities.

KEYWORDS

COVID-19, impact, Nepal, people with disabilities, socio-economic status

1 | INTRODUCTION

Coronavirus was first identified in China in late December 2019 causing severe respiratory disease including pneumonia, cough, and fever. COVID-19 was declared a pandemic by the World Health Organization on March 11, 2020, after widespread detection around the world. By February 4, 2022, globally 386, 548, 962 people were affected by COVID-19 with 5,705,754 confirmed deaths (World Health Organisation, 2022).

On January 3, 2020, a first case of COVID-19 was detected in a Nepalese student who had been studying in Wuhan (Shrestha et al., 2020). After Nepal-China air and land boarders were closed on January 21, 2020, the Nepal government announced the suspension of all international flights and declared a countrywide lockdown on March 23, 2020 (Government of Nepal, 2020). By February 4, 2022, a total of 964,119 people had tested positive for COVID-19 across the country and 11,794 people died due to this virus (World Health Organisation, 2022). At

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the very beginning, the Eastern part of the country (Udayapur district) is understood to have been a hotspot of the virus transmission where 32 people tested positive, after which further cases were detected in other districts of Nepal and continued to increase rapidly.

According to Asim et al. (2020), there is limited coordination among stakeholders in the management of health care with few policies in place for infection prevention and control (IPC). Due to high population density, Nepal is vulnerable to mass outbreak, given difficulties maintaining physical distancing, poor hygiene, a low rate of health literacy (Asim et al., 2020), and difficulties in predicting the severity of the outbreak. People with disabilities are found to be more at risk, as relevant agencies did not prioritize them, compounding the disadvantage and social, economical, political, and physical marginalization experienced by them. Information made available through the Nepal Ministry of Health and Population in coordination with the World Health Organization (WHO) through the SitRep#296 (situation report) for the period to December 1, 2020, provided data on the impact of COVID-19 by gender, age, district, and province but did not specify impacts for people with disabilities.

This study was carried out to explore the effects of COVID-19 on the lives of people with disabilities in rural Nepal. This exploration will assist to development of policies and actions to address the issues faced by people with disabilities during the COVID-19 crisis. This paper is presented in six sections addressing the country context of Nepal and people with disabilities; the theory of intersectionality; the study's research method; the findings of the study and discussion; and finally conclude.

2 | PEOPLE WITH DISABILITY AND DISASTER IN NEPAL

Nepal is a multi-lingual, multi-cultural, multi-religion, and multi-ethnic country having a pluralistic and landlocked identity between two countries, China and India, in South Asia. Based on the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (2006), a comprehensive set of rights in relation to access to education, social justice, and proportional representation in the local bodies has been guaranteed to people with disabilities in the constitution of Nepal (2015). Under clause 10 of chapter 3 of "The Act Relating to Rights of Persons with Disabilities, 2017", people with disabilities have the right to security, rescue, and protection during armed conflict, and emergencies (Government of Nepal, 2017).

Despite these legislative initiatives, people with disabilities in Nepal experience multiple barriers. For instance, people with disabilities regularly feel neglected in many areas of daily life, experience difficulties accessing services from government offices, have less access to transportation, education, and health, experience discrimination in workplaces, and feel that they are not treated with dignity (United Nations Development Programme Nepal, 2016). The majority of children with disabilities, especially those who have intellectual disabilities, hearing and visual impairments, mental illness, and multiple disabilities, are denied access to basic education which is impacting their quality of life. Many people who are blind are disadvantaged by lack of disability friendly infrastructure (Eide et al., 2016). People with disabilities have reported inaccessibility of government offices (United Nations Development Programme Nepal, 2016). Reports reflect that in Nepal, few people with disabilities have been found to know their rights, have limited participation in politics, and there is little awareness of disability among the general population (Ansari, 2018).

Disability statistics vary across studies in Nepal. As per national census data of 2011, people with disabilities comprise 1.94 percent (513,321) of the total population (26,494,504) (Central Bureau of Statistics, 2012). However, disability data in Nepal are considered to be underrepresented by some scholars and disability activists (Thapaliya, 2016). Moreover, Disabled People Organizations (DPOs) have claimed that the total disability ratio might have increased due to the devastating earthquake of Nepal in 2015. The social protection strategies of the government of Nepal seek to reduce poverty experienced by marginalized people. However, social protection appears to be very limited for people with disabilities in Nepal.

Nepal is a disaster-prone country. The nation is in the top 20 of all the multi-hazard countries in the world. Over 80 percent of the population is likely to be in danger of natural hazards (Ministry of Home Affairs, 2017) including earthquakes, droughts, floods, landslides, extreme temperatures, and Glacier Lake Outburst Floods (GLOFs) (United Nations Office for Disaster Risk Reduction, 2019). The 2015 Nepal earthquake is considered to have been the deadliest natural disaster in the history of Nepal, causing 8,970 casualties and 22,302 injuries (Ministry of Home Affairs, 2017). As Nepal still progresses with recovery from this earthquake and the attainment of medium to long-term reconstruction, the COVID-19 pandemic has disrupted progress.

Consciousness about the intrinsic vulnerabilities of people with disabilities during disasters is increasing, in part because of the impact of the global disability discourse enunciated through, for example, the Sustainable Development Goals-SDGs (2006). The Sustainable Development Goals set down to be achieved by 2030 incorporate recommendations for the inclusion of people with disabilities. Nepal has a significant chance to operationalize those standards and to establish enactments that reflect Nepal's 2009 endorsement of the Convention on the Rights of Persons with Disabilities (CRPD) (Lord et al., 2016). For people with disabilities in Nepal, the challenge of addressing the different post-earthquake experiences is made more complex by the intersectional discriminations associated with caste, gender, ethnicity, and class (Arora, 2020).

In Nepal's main emergencies such as the earthquake, and now the pandemic, the top-down response system has not connected with its most disadvantaged citizens. In dealing with the COVID-19 crisis, plans for preparedness, response, and recovery are inadequate, although there is also a view that the government of Nepal is attempting to control the situation (Koirala & Acharya, 2020). Yet, issues and concerns of people with disabilities remained historically neglected, structurally unaddressed, socially stigmatized, and culturally unexplored. COVID-19 has further exposed people with disabilities to infection, multiple barriers such as socio-economic barriers, and discrimination (National federation of the disabled Nepal, 2020).

3 | THEORY OF INTERSECTIONALITY

The theory of intersectionality was first coined by the legal scholar Kimberly Crenshaw (1989). It refers to "the interactivity of social identity structures such as race, class, and gender in fostering life experiences, especially experiences of privilege and oppression" (Gopaldas, 2013, p.1). Collins and Bilge (2020, p.1) described that:

Intersectionality investigates how intersecting power relations influence social relations across diverse societies as well as individual experiences in everyday life. As an analytical tool, intersectionality views categories of race, class, gender, sexuality, class, nation, ability, ethnicity, and age-among others-as interrelated and mutually shaping one another. Intersectionality is a way of understanding and explaining complexity in the world, in people, and in human experiences.

People with disabilities are one of the most disadvantaged groups in society. They experience multiple forms of discrimination and exclusions in society. For instance, people with disabilities might experience discrimination from institutions such as social or financial institutions, or they could be discriminated from their family members, or based on the age, gender, and geographic locations (Ravnbøl, 2009). The theory of intersectionality provides an insight to understand how multiple forms of disadvantages and oppression exclude people with disabilities in accessing socio-economic, political, and educational spheres. It further assists to explore the system of power which has a significant influence over the lives of disadvantaged people (Blyth et al., 2020). This study utilized the theory of intersectionality to understand the multidimensional challenges that people with disabilities are experiencing during the COVID-19 pandemic in Nepal.

4 | RESEARCH DESIGN

This study used qualitative data to explore the effect of COVID-19 on the lives of poor people with disabilities in rural Nepal using data collected by READ Nepal, a non-governmental organization that has been in operation since 1991. Part of its operations includes working with communities in South Asia through READ Community Library and Resource Centers ("READ Centers"), community-owned and managed development hubs that bring educational, economic, and other community development programs to entire communities. This organization also focuses on educational and learning programs for girls, women, and vulnerable groups such as people with disabilities, and elderly people to empower them as individuals. In the current COVID-19 situation, READ Nepal has been monitoring the circumstances of marginalized people in Nepal.

This study used semi-structured in-depth interviews to collect data. A total of 20 participants were interviewed, and among them, 15 interviewees were people with disabilities, identified through the programs of READ Nepal, and five were senior officials of Disabled People Organisations (DPOs) in Nepal. Out of 15 participants with disabilities, five people had physical disabilities (33 percent), four people had hearing impairments (27 percent), three people had visual impairments (20 percent), two people had multiple disabilities (13 percent), and one had an intellectual disability (7 percent). Among the interviewees with disabilities, eight were male and seven were female. Most of the participants' (nine out of fifteen people with disabilities) were in the age range between 26 and 40 years. These interviews were conducted by telephone. During the pandemic, this technique of interview was considered safest, but it was also challenging because of the limited opportunity to build rapport with the participants via telephone, and because of the poor mobile network in the rural area. However, the interviews were preceded by discussions with interviewees that introduced the research project and its objective, informal conversation with the participants, and more importantly, familiarity of READ Nepal's development activities in local areas. This required several calls to reach and engage with remote participants thanks to the READ Nepal's local staff who assisted in the process of conducting this research. In few cases and when relevant, participants such as people with hearing impairments provided their written answers to the research questions. The participants were interviewed on issues such as their daily living and family conditions and challenges faced in terms of accessing basic services such as education, health, employment, and income, as well as their expectations of support from families and government. In addition to that semi-structured in-depth interviews were conducted with five key stakeholders who were senior officials of Disabled People Organisations (DPOs) in Nepal. In these interviews, the experiences and observations of these officials on the impact of COVID-19 on the lives of people

with disabilities were recorded and analyzed. The data collected as part of this study have been used as per the data protocol management of READ Nepal (RN) where no individual information is disclosed. Therefore, participants' names, which are mentioned in this research, are pseudonyms. The objective of this study was to examine the impact of COVID-19 on people with disabilities to identify necessary measures including policy interventions to address those challenges to protect the rights of people with disabilities in Nepal.

This study followed Braun and Clarke's (2006) six-step procedures for thematic analysis. The interviews were transcribed, read, and reread for more understanding. Then, codes were generated which identified primary themes. These themes which emerged included difficulties faced by people with disabilities in earning a living, uncertainty in continuing education, and scarcity of health services. These themes represent the areas most significantly impacted by COVID-19 on the lives of people with disabilities.

5 | FINDINGS

5.1 | Difficulties in earning a living

COVID-19 has a severe consequence over the lives of people with disabilities that has limited their capacity to earn income. This study revealed that COVID-19 affected many people with disabilities in such a way that they became unable to bear daily expenses due to further interruption of what may already have been an irregular and small income. As a result, many of them started borrowing money from informal sources such as local money lenders who charge higher interest rates against credit. For example, a man with a visual impairment explained that his income opportunities became limited due to COVID-19. He was facing difficulties managing the household's expenses, child's education, and health expenses due to the interruption of all income and income activities in the lockdown situation. In his own statement:

It is very difficult for me to earn a living now due to this lockdown. Before this situation, sometimes I used to earn money by doing labour work and now facing challenges to manage the household expenses. Recently I have borrowed money from the local money lender to run my family, but I am not sure how I could repay the debt if this situation goes for a long time.

This research also revealed that participants were living in miserable conditions and they could not be taken to the hospital for medical examination due to the poor economic conditions. In another case, a woman with a physical disability shared that she and her family had just migrated to a low land area from the hill. One and a half months after they migrated to a new home, the area was locked down due to COVID-19. The government had completely restricted the movement in this area that made it difficult for them to move. Her father used to earn in India, but now he lost his income and difficult to survive because of the restrictions on travel. Her family has no land except for the house. They are daily wage earners, but due to COVID-19, there is no work for them. She became frustrated and explained that if this situation continues for a long time, they will starve to death.

COVID-19 had a major impact on people who are deaf. One of the senior officials from the National Federation of the Deaf, Nepal, explained that those people who are deaf were experiencing loss of jobs and provided examples of people with disabilities who had been street musicians whose living was ended by COVID-19 restrictions. He further added that there have been reports that two people who were deaf committed suicide. It was reported that many people with disabilities and their family members urged government to provide at least basic food at this time.

Most of the marginalized groups including people with disabilities are disadvantaged and always in a state of crisis. This study found that during this COVID-19 period, people living in poverty have limited access to the government's social protection programs. A participant with visual impairment stated that she did not receive any relief from the local government. She explained:

The relief distributed by the local government was not given to us. Everyone hates the disabled, poor, and old age person. No one has heard our voice. I had heard that the government provides special services to people with disabilities, and senior citizens but in reality, it is all lies. During this pandemic situation, we need immediate relief support.

Due to this kind of deprivation, a man with a visual impairment stated that he has no more expectations from the local government but only wants to see that local government protect their rights and respect to people with disabilities. However, despite criticism, some people with disabilities are entitled to receive the government's financial benefits but due to lockdown, it becomes hard for them to access those services. For instance, a woman with an intellectual disability explained that the government of Nepal has given her a blue identity card (ID) by recognizing her as a person with severe disability and provided some monthly allowances as well. However, due to the current lockdown and travel limitations, she has not been able to get those allowances.

5.2 | Uncertainty in continuing education

This study found that many students with disabilities were unable to continue their education as schools were closed. For instance, due to COVID-19, a 15-year-old girl with a physical disability explained that she has lost all opportunities to continue her studies, unable to attend regular classes, and complete assessments and examinations. She has no job and depends upon the family income. She feared that if this situation continued that she could not return to her education given the family's poverty.

One of the senior officials from the Nepal association of the blind explained that during this COVID-19, most of the people who are blind did not have any access to the online education system offered by the government of Nepal. He further explained that almost all blind students have no access to assistive technology during lockdown and they are deprived of the right to education due to this COVID-19. A participant who has a visual impairment was concerned for the education of his child explaining that as a person with a disability living in poverty as a result of COVID-19, he was not sure how he would be able to continue supporting the education of his children.

Another female participant with visual impairment stated that:

I heard that the government of Nepal distributed the Corporate User Group (CUG) SIM card for online reading provision services to the all-remote students through school which is free of cost. But the teacher at the school neither talked about these services nor operated the online classes during the lockdown period. So, we are feeling more exclusion from access to education facilities. When I asked our headteacher about this provision, he told me that they (teachers) hadn't been trained about the operation of these services. Therefore, they couldn't start the online classes due to the lack of technical knowledge.

Accessing education facilities for people with hearing impairment found very challenging. For instance, a male participant with hearing impairment expressed that:

There is no sign language school and education in our area. I want to read beyond basic education, but no one understands my communication even in my house as well. Therefore, people like us are deprived of the higher-level education apart from basic education in our rural location. Due to COVID, I can't explore other areas such as in the city where I can get these facilities.

In effect, this section summarizes that due to COVID-19, people with disabilities have limited opportunities to access education and the assistive technologies they may require, affecting their ability to complete future educational studies.

5.3 | Scarcity of health services

Accessing health services during the COVID-19 pandemic presented further challenges for many people with disabilities. Many people with disabilities were unaware of the coronavirus. For instance, a female participant with multiple disabilities (hearing impairment and physical disability) described that people with hearing impairments like her were unaware of the coronavirus. She further stated that it would have been very helpful to get some accessible information and awareness support about this virus.

In another case, a female participant who was blind and also the secretary of a local Blind Association shared her experiences:

Quarantine was remained very difficult for the visually impaired person. Food was thrown outside from the window, and we had to search by touching the ground and there was no person to guide us on the way to the restroom as well. We couldn't get the basin for handwashing, so the environment to follow quarantine was not accessible to us.

A male person with a physical disability shared that:

During this time, we have been facing a great scarcity of medical equipment like diapers, urinal bags, positioning devices, etc. We couldn't get any assistance from the local government.

Another female participant who had a visual impairment shared her experience:

Women with visual impairments could not admit to the hospital for delivery the baby. As there was no regular check-up at the hospital, we had to suffer a lot when the hospital told us that we could not do a check-up.

Moreover, a female participant who was blind and also the secretary of a local Blind Association described that an ambulance service provider did not agree to provide services when they recognized that the customer was a blind person. She further shared that when she asked the hotline for the ambulance number, they (people who operates hotlines) used to provide the wrong number. This is why she experienced discrimination during this COVID period.

A person with a visual impairment who had been sick for a month had been unable to visit a doctor in a specialized hospital in the city and seek health care during the lockdown. In another case, a woman with a physical disability who could not actively use one of her hands properly was advised that the problem with her hand required an operation, but due to her poor financial condition, she had not been able to proceed with the operation. When in pain, she used to go to the nearby health service center for general treatment but due to lockdown, this was no longer possible.

In addition, a woman with an intellectual disability shared that she was discriminated by a medical professional once she managed to visit a local hospital. When she went to a local health service center to check up for fever, the doctor had rebuked her by accusing the probability of virus transmission. According to her, she was treated as if she was not a human being.

Community leaders stated that supports provided to people with disabilities was interrupted, especially for those experiencing mental illness, and in some cases increasing the person's vulnerability and exposure to infection through community transmission of COVID-19. A senior official from the National Federation of Physical Disabled Nepal explained that most of the time, people with disabilities had been in isolation from the entire community during the COVID-19 situation leaving them susceptible to psychosocial problems such as depression. He spoke also of the need for continued services to people with physical disabilities requiring clinical supports.

The findings reinforced how many poor people with disabilities have experienced health vulnerability during COVID-19 especially in terms of accessibility of health services and inappropriateness of health responses.

6 | DISCUSSION

This study presented the socio-economic impacts of COVID-19 on people with disabilities in rural Nepal. COVID-19 negatively impacted the income opportunities of people with disabilities especially for those who were fully dependent on the daily wage income, leaving them unable to meet their daily household, educational, and health costs. These findings are consistent with the findings of another study conducted in Nepal (Gurunga, 2021) and (Humanity & Inclusion, 2020). To survive, many people with disabilities are putting themselves into a credit trap which will likely have longer term impacts over their lives.

While Sarker (2015, 2020) argues that generally people with disabilities experience oppression and discrimination, it became apparent from this study that people with disabilities are experiencing further exclusions and mental stress during the COVID-19 pandemic. Multiple studies (see Devkota et al., 2021; Poudel & Subedi, 2020) in Nepal found that COVID-19 created severe mental health issues. This study also found that the compounded vulnerabilities that people with disabilities experienced contributed to their psychosocial stresses. Moreover, this was also found in this study where participants experienced further stigma, extreme stress, and uncertainty.

This study explored that people with disabilities had limited access to available information about COVID-19. Article 21 of UNCRPD urges to ensure equal access to information for people with disabilities. Despite this provision people with disabilities had limited access to information about COVID-19. Moreover, this research further found that awareness about COVID-19 and also customized communication was very limited in Nepal especially for people with different types of disabilities. This unavailability of information puts them at health risk related to COVID-19. These findings are similar to the findings of other studies conducted in Nepal (Gurunga, 2021; Rohwerder et al., 2021).

This study observed that the government has been following a "one size fits all" approach to deliver services. This approach does not address diverse needs of people with different types of disabilities for their right to education, livelihood, health, information, and communication technology. These findings are echoed in other studies (Poudel & Subedi, 2020; Rohwerder et al., 2021) on Nepal. One of the senior officials of a disability organization explained that the Ministry of Education, Science, and Technology could have developed the school course-based audio book, but they have not been provided, which shows how the government has addressed the issue of blind students in Nepal.

This research further found that some people who are deaf or have intellectual disability or visual impairment experience complex circumstance. For instance, communication is a big problem for the deaf. The government has started teaching online, but those who cannot hear or speak, especially those living in rural areas, are having a hard time because they do not have access to the internet, and they have very little access to television. People with mental illness or intellectual disability are having the same effect.

Therefore, to ensure inclusion, all the relevant stakeholders should be conscious to address the need of people with disabilities, particularly for those who have mental illness, speech disorders, or are deaf. More importantly, special focus should be given to women and children with disabilities who have a mental illness during this COVID-19 period. Additionally, the provision of urgent support especially basic health-related medicines and protection materials along with basic food is critical. People with disabilities who are in poverty and also living in rural areas need special care for accessing medical services. Some remote areas have no hospitals; thus, they need to come to the city, which becomes challenging for them due to the cost and time and health issues especially at this pandemic time.

Although on a limited scale, the government is providing disability allowances to some people with disabilities. However, due to COVID-19 and lockdown, many of the beneficiaries could not access that allowance. Thus, access to cash benefits should be ensured at this time as early as possible in a way that requires less or no human interaction when necessary. In this case, digital financial services could be an effective way to provide allowances. Furthermore, since most of the people with disabilities lost their income-earning opportunities, government and organizations should focus on sustainable livelihood options for people with disabilities soon. The government should also introduce a special financial incentive package to protect the employment of people with disabilities during this pandemic time.

This study supports the need for meaningful collaborations involving government, non-government organizations, community-based organizations, and other stakeholders to support the people with disabilities during this pandemic. The close consultation and active engagement of people with disabilities is critical to ensure the right-based response to pandemic that is inclusive and responsive to the needs of people with disabilities. Based on consultations, the support for financial aid and opportunities, inclusive educational programs can be designed and delivered to people with disabilities. Training and awareness raising of healthcare workers and other stakeholders involved in community service is critical to prevent discrimination and bias against people with disabilities. Establishing close coordination with the guardians and caregivers is also important to be informed about the situation and need of people with disabilities. The community and voluntary networks can carry out the monitoring activities particularly of those living in isolation by proactive outreach.

Finally, since people with disabilities are mostly out of social networks, there could be the efforts toward connecting people with disabilities with their disability community in this pandemic. This might assist them to understand better each other's circumstances and share knowledge among themselves. Because without these, they become more isolated, and especially those who have no family or are abandoned might face severe challenges.

7 | CONCLUSION

Despite few initiatives taken by the government of Nepal and the disabled people organizations over the years in Nepal, people with disabilities are still marginalized and disadvantaged. They have very limited access to existing resources such as education, health, transportation, employment opportunity, and social safety net programs. This pandemic disempowered and impacted the lives of people with disabilities in such as a way that requires special attention from the government and relevant stakeholders such non-governmental organization to empower people with disabilities. Gender friendly participation of people with disabilities in the existing and future interventions at national and local level might provide an opportunity to people with disabilities to be heard and that voice might reflect in the strategies to address the consequences that people with disabilities are experiencing in Nepal due to the pandemic. This study has some limitations: one of these is a small sample size, the other one is the limitations to conduct interviews with people with diverse types of disabilities from both urban and rural areas such as people with Down Syndrome, mental illness, and speech disorder. However, despite these limitations, this study will provide a significant insight of the effects of COVID-19 on the lives of people with different types of disabilities.

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