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Pain and Plight of People with Disabilities during COVID-19 Pandemic: Reflections from Nepal

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Recently, in a public forum Lindsay Lee, a WHO Technical Officer with expertise in disability issues, mentioned, “What worries me perhaps more than anything is just the existing barriers that people with disabilities face. I can speak for this myself, personally. Lindsay further explained that health care access is already difficult for some people with disabilities, even in high-income locations. Other barriers include physical obstacles, discriminatory laws and existing stigma,” she said.

The global contagion of COVID-19 has made us humans realize that every individual is vulnerable to the virus. However, the pandemic and subsequent lockdown situation has led to a disproportionate impact on some groups of people more than others, such as People with Disabilities (PwDs) whose challenges are further intensified. The research findings have shown that PwDs were unequally affected during the influenza pandemic. The lack of epidemiological data was one reason among others, which had influenced negatively in preparedness plans and responses. Moreover, The World Health Organization (WHO) explains that PwDs are at a higher risk of contracting COVID-19 for following reasons (a) physical barriers to access hygiene facilities (b) need to touch things (c) difficulty in enacting social/physical distancing (d) difficulty accessing information.

The attitudinal barrier has remained equally challenging, consequently causing multiple problems such as mental, psychological, social, and economic for PwDs. In this backdrop, this writing unfolds the pain and plight of PwDs and their everyday struggle while living through pandemic in a low-resource setting country like Nepal.

Lindsay’s statement was to a greater extent a concern and a problem of PwDs and their families living and struggling across the world, especially in the low-resource countries and weak health systems during the current crisis. The population of PwDs is substantial, approximately accounting one billion worldwide of which 690 million are in the Asia and the Pacific region, and approximately over half-a-million in Nepal. That number, however, is often contested. For example, the activists working in the disability sector in Nepal argue that the number of PwDs is three million, who are collectively fighting against this pandemic in the middle of a myriad of challenges and profound problems. PwDs are likely to face more difficulties while staying in self-isolation and quarantine due to inaccessible infrastructure and facilities.

These lived human experiences have never received adequate attention in public health arena. Consequently, these important issues are not only remained in shadow but also the health and public health needs of PwDs are largely ignored .

Anthropologists Faye Ginsburg and Rayna Rapp (2019) commented that despite the overarching approach to embracing human diversity, anthropological explorations of disability were relatively rare until the late 20th century.

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Thus, the cross-cultural understanding of disability is not clear. The continuation of the trend largely has contributed to overlooking the sensorial understanding and embodied experience of PwDs living through COVID-19.

As the issues and concerns of PwDs remain historically overlooked, structurally unaddressed, socially stigmatized, and culturally unexplored; people perceive these issues as 'taken for granted'. Conversely, present crisis demands cooperation and collaboration among human more than ever with respecting and realizing diverse needs for overcoming this disease. Yet, it seems primarily the governments are paying only scant attention to the unique needs and requirements of PwDs, forgetting the fact that failing to address the issues at this critical juncture would be counterproductive and put a serious threat to entire humanity. The repercussions of our own ignorance are likely be far and deep, which are difficult to quantify and measure accurately.

Accessibility—A Key Challenge/Barrier

Globally, PwDs are facing health disparities even in the normal situation and evidently most of them reside in low- and middle-income countries (LMICs) and low-resource settings. Nepal is not an exception where PwDs have been facing historically accessibility issues in the public places, including health system. This situation demands even greater need for inclusive information and guidelines for prevention and protection of PwDs across different contexts. Absence of or minimum understanding regarding PwDs have led to no focused programs for catering to the unique needs and requirements of PwDs during pandemic have made lives of PwDs more complicated and even exacerbated their existing situation. Similarly, the case of adopting social/physical distancing for PwDs is not less challenging due to an inaccessible environment for independent living and need for constant support of personal assistant(s) even for maintaining personal hygiene and sanitation. Lack of accessible hand-washing facilities, considering the individual needs of PwDs, has created a challenging situation for them to maintain regular/frequent hand washing—one of the recommended practices to prevent COVID 19. This could be further explained by the sketch posted/shared on social media posted by the Blind Youth Association Nepal, a disabled peoples' organization in Nepal. The sketch at the left says 'to avoid COVID-19 wash your hand'. In contrast, a wheel chair user is struggling to wash hand because hand-washing facility is not user-friendly.

Information, Education and Communication (IEC) materials, on COVID-19 are not friendly to all kinds of PwDs either. Theoretically, IEC materials should be made available in different formats including audio, Braille, large print, and easy-to-understand formats, using local language would promote accessibility for all. Conversely, many required accessibility features are yet mostly lacking. Nepal has recently introduced sign language interpretation features in the daily media brief on COVID-19 update by the Ministry of Health and Population. Similarly, Epidemiology and Disease Control Department in collaboration with other collaborators has developed a video clip of 2 minutes 32 seconds promoting awareness among PwDs to safe themselves from COVID-19. These are undoubtedly welcome steps towards inclusive public health system. However, there is a long way to go for making public health information and measure inclusive. A situation analysis report on impact of COVID-19 and lockdown on PwDs in Nepal by NFD-N has revealed that over 41 percent of PwDs were found to have a little knowledge and 6 percent were completely unaware about general information about COVID-19 due to inaccessible information and awareness materials. Furthermore, the report notes that more than 42 percent have little knowledge and 7 percent have completely no knowledge about the measures to be taken to stay safe from COVID-19 infection. The WHO has mentioned that key stakeholders can mitigate the differential impact of COVID-19 on PwDs through collective actions protective measures.

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Policies and Practices—Lost in Translation

Nepal has a relatively short history of recognizing concerns of PwDs in the policy landscape. These were first addressed with an endorsement Disabled Protection and Welfare Act 1982, in response to the UN promulgation of Action Concerning to Disabled Persons, 1982. The Act sought to provide several rights and facilities, including free medical examinations. Subsequently, several other policy frameworks for easing the everyday lives of PwDs during crisis and the general situations. The United Nations Convention on Persons with Disabilities (UNCRPD-2006) Article-11 stated that the country is responsible for taking all necessary measures to ensure the protection and safety of PwDs in the situations of risk, including in humanitarian emergencies and the occurrence of natural disasters. As a signatory country, Nepal is officially obliged to follow and act on the provisions accordingly.

Similarly, Article 18 of the Constitution of Nepal 2015 has granted equality to everyone noting that no discrimination should be made against an individual(s) based on socio-demographic characteristics and physical conditions. Further, the Government of Nepal has endorsed the Disaster Risk and Management Act (2017). The Act has spelled out that special provisions should be designed and developed owing to the different needs and requirements of particularly for specific groups of people including, PwDs, senior citizens, among others, during the disaster, emergency, and crisis. The Act was developed in Nepal following the Sendai Framework for Disaster Risk Reduction (2015-2030), a comprehensive and inclusive framework for mitigation of the risk during the disaster, emergency, and health crisis. Lately, the incorporation of disability in the Sustainable Development Goals—with the slogan ‘leaving no one behind’ and Universal Health Coverage. Similarly, Health Sector Emergency Response Plan COVID-19 pandemic, which explained that quarantine facilities would ensure the special needs of vulnerable groups including PwDs. Further, risk communication messages will be designed and developed in accessible formats suitable to different types of PwDs. ‘A General Guidelines for Persons with Disabilities and All Stakeholders on Disability Inclusive Response Against COVID-19 Pandemic endorsed by National Federation of Disabled-Nepal (NFD-N), an umbrella association of disabled people organizations in Nepal. For making health responses and public health measures inclusive to disability in order to mitigate the unequal impact of COVID-19 on PwDs.

Nevertheless, the implementation of these policy provisions and legal frameworks is minimal. It shows the high in rhetoric and low in action. And, the Government of Nepal has not paid adequate attention to making health responses disability-friendly in the emergence of COVID-19. This shows the insensitivity and biased attitude of the Government towards PwDs and their issues even at the time of crisis. Consequently, PwDs are continually struggling to live their lives amid the visible and invisible challenges. Thus, the frameworks and provisions alone are not enough; strong political will and commitment for their effective and efficient implementation are equally crucial.

Everyday Challenges of PwDs during Pandemic—Unnoticed Stories of Humanity

Like many other countries across the world, Nepal endorsed the lockdown first on 24th March 2020 and it was extended for several times lately on 30th May 2020 which will last 14th June 2020. Despite of positive aspect of lockdown, it has had repercussions in many sectors of the country, and it has made the life of PwDs even more complicated. Also, similar to the virus, everyone knows little about how long it will last for. Further, both in affluent countries and low-resource settings, PwDs are facing problems in relation to accessing their essential medical services and essential medical equipment/aid such as regular therapeutic services, catheters, urine bags, diapers, among others. For instance, hundreds of people living with hemophilia are already experiencing a shortage of ‘Factor’ the medicines; they take regularly.

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Recently published news reported that, Sharmila Tamang is a 21-year old wheelchair user, and she lives in Kathmandu, mentioned “I cannot visit the hospital alone either and people do not want to touch me due to fear of COVID-19 contamination,” Sharmila told the newspaper. Sharmila further complained that she has been using the same CIP pipe for long due to the pandemic-induced lockdown. Similarly, a 19-year Babita Phuyal is another wheelchair user; originally, from Dolakha district in central Nepal, currently living in Kathmandu shared a similar story. “I cannot go to the toilet for peeing in a wheelchair, but I need to use the CIP pipe for peeing. The body is regulating entirely on medical equipment, and it has been difficult as the medical equipment is not easily available these days,” she added. “The situation has been even more difficult during the period as I have not been able to go to buy [sanitary] pads”. “The lockdown has hit on the head, people like me,” Babita added further. The findings from the recent report by NFD-N has shown that 45 percent of PwDs are in the urgent need of hygiene materials such as catheter, tube, mask, sanitizer, urine bag, diaper in Nepal during pandemic and subsequent lockdown. These are not only the personal struggles or the ‘lived experiences’ of PwDs while living through pandemic. These inadequate and non-inclusive institutional responses have made the PwDs feel neglected, unreasonably treated and unfairly denied during the crisis.

Socio-cultural Context—A Foundation

Medical anthropologists like Paul Farmer (2001) and Merrill Singer (1986) have shared their extensive knowledge in social inequality and health disparities, highlighting the role of social determinants of health. Farmer argues that the social conditions significantly determine the risk of infection. And Singer explains the significant influence of local context, historic, demographic and cultural patterns on health care. In the broader Nepali context, PwDs are still facing several challenges and problems in their personal and public lives. People perceive disability more as a physical impairment and a personal problem; thus, the responsibility of managing disability entirely falls under the family sphere. Even worse, disability is perceived as a condition resulting from the curse of God as wrongdoing in the previous life. The use of derogatory terms for referring to one's disability is pervasive. This has led to social discrimination and biased attitude, negligence against PwDs. This makes PwDs hesitant to go for testing and treating COVID-19 to the health intuitions, and they are not motivated either. This situation not only makes themselves more vulnerable in the community but also puts the entire community at the risk of infection.

The dearth of studies and explorations in this area has made it difficult to understand the depth and breadth of the subject matter coupled with minimum knowledge and awareness on the diversities within disability among community people have made situation even more complex. The evidence has shown that the situation will worsen if disability intersects with other socio-demographic characteristics, including gender, age, caste and ethnicity, income, and place of residence, among others. Thus, understanding and exploring in the social and cultural milieu and politico-historical context could offer comprehensive insight and make better sense.

Persistent Problem: Call for Collaboration

Historically, PwDs have been facing numerous challenges while accessing health care facilities and services in Nepal during usual and emergency time for several reasons. These include structural, social, and political among others. Despite the greater vulnerabilities of PwDs in the crisis, scant attention has provided to the issues and concerns of PwDs in Nepal during COVID-19 and the subsequent lockdown. This has created a differential impact on PwDs and intensified their suffering and hardship. Further, this situation has made them more susceptible to COVID-19 infection.

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This situation likely to promote health disparities and health inequalities even deeper and wider. This should be understood and explained, linking to the entire health system, and broader context wherein all these responses are designed and implemented. The present pandemic not only has created an unequal impact on PwDs but also opened window of opportunity for creating even more inclusive and better accessible health system collectively and collaboratively. This in turn would contribute not only to address the health needs of the needy people, but also to support to save humanity, promote social justice in health, and ultimately to contain the virus.

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