

Population Review

Volume 59, Number 2, 2020

Type: Policy Note, pp. 180-188

Impact of Coronavirus (COVID-19) Pandemic on Persons with Disabilities and Caregivers

Authors: Bilal Ahmad Khan, Wakar Amin Zargar, Shazia Manzoor, Danish Iqbal Mattoo, Aadil Bashir, Shabir Ahmad Najar, Zahid Maqbool Pandit

Affiliations: Department of Social Work, University of Kashmir (Khan); Department of Social Work, University of Kashmir (Zargar); Department of Social Work, University of Kashmir (Manzoor); Department of Management Studies, University of Kashmir (Mattoo); Department of Social Work, University of Kashmir (Bashir); Centre of Central Asian Studies, University of Kashmir (Najar); Department of Social Work, University of Kashmir (Pandit)

Corresponding author/address: Bilal Ahmad Khan, Research Scholar, Department of Social Work, University of Kashmir; email: Khanbilz@gmail.com

Abstract

Roughly 1.3 billion persons with disabilities worldwide (80 per cent living in developing countries) are being marginalized by factors related to the coronavirus (COVID-19) pandemic. For the first time in a long time, huge numbers of people are feeling segregated from 'normal life' and are being quarantined in homes and hospitals. Due to apparently endless and restrictive lockdown rules, patterns of social isolation and detachment appear far from temporary. The present paper aims to highlight the issues and challenges faced by persons with disabilities and their caregivers during the coronavirus pandemic.

Keywords

Coronavirus, pandemic, persons with disability, caregivers, challenges, COVID-19

Introduction

COVID-19 is caused by a new coronavirus called SARS-CoV-2. WHO first learned about this new virus on 31 December 2019, following a report of a cluster of cases of ‘viral pneumonia’ in Wuhan, People’s Republic of China. The hunt for the precise origin of the virus is ongoing; it may have come from a ‘wet market’ in Wuhan or it may have come from a P4 laboratory at the Wuhan Institute of Virology (Adhikari *et al.*, 2020). Coronavirus has its place in the family of viruses and can cause various symptoms, such as pneumonia, fever, difficulty in breathing and lung infections, among others. The virus is common in animals around the world. The disease is transmitted by direct contact with infected droplets, and the incubation period ranges from 2 to 14 days. COVID 19 is in general, mild in most age groups (particularly the young), but it can be very serious in elderly people who have underlying medical problems (e.g. diabetes, chronic respiratory disorders, and cardiovascular disease), leading to deadly complications such as pneumonia, acute respiratory distress and organ dysfunction (Cheke *et al.*,2020). COVID-19 has since spread to several countries around the world, and the global mainstream media has become increasingly vocal about controversial issues like social distancing, wearing masks and quarantining.

Definition of terms and concepts

Social and physical distancing

Social distance is defined as the increase in physical space between people to avoid deliberately spreading diseases. Canceling the chances of attracting a crowd is an example of social and physical distancing (Maragakis, 2020).

Isolation

Isolation is a term used in health care that means keeping people without infection away from people infected with a disease that is communicable. Isolation can occur at home or in a hospital or care facility. Special personal protective equipment is used in health-care facilities to care for these patients (Center for Disease Control, 2017).

Self-quarantine

Quarantine involves isolating and controlling the movement of people who have been exposed to a contagious disease to let them know they are sick, thus minimizing the risk of infecting others (CDC, 2017; Brooks *et al.*, 2020). People who have been exposed to the novel coronavirus and who are at risk of contracting COVID-19 can practice quarantine on their own. Health experts have advised that one should be in quarantine for 14 days. Two weeks is thought to be enough time to discover if a person is infected, the seriousness of the infection and how contagious the infected person is to other people (Maragakis, 2020). Self-quarantine involves:

1. Using standard hygiene and washing hands frequently;
2. Not sharing things like towels and utensils;
3. Staying at home;
4. Not having visitors; and
5. Staying at least 6 feet away from other people in your household.

This definition differs from *isolation*, which is the separation of people who have been diagnosed with a contagious disease from people who are not sick; however, the two terms are often used interchangeably, especially in communication with the public (Brooks *et al.*, 2020)

Disability and pandemics

A pandemic is a worldwide epidemic in which a disease spreads easily and rapidly (Porta, Miquel & ed, 2008). Pandemics are rare but can be very deadly. An influenza pandemic occurs when an influenza virus changes and becomes a new strain against which people have little or no immunity. This new strain is easily spread from person to person (WHO, 2010). Throughout recorded history, influenza has been the major cause of pandemics. In the 20th century, three influenza pandemics were recorded in three different quarters of the century. The deadliest was the Spanish flu (from 1918-1920), which caused an estimated 20-50 million deaths worldwide. The Spanish flu virus originated from H1N1 influenza A virus. The Spanish flu pandemic was followed by the Asian flu pandemic in 1957-1958, causing an estimated 1.1 million deaths worldwide. More recently, in 1968, the Hong Kong flu pandemic resulted in an estimated 4-5 million human lives worldwide (WHO: Europe, 2020).

COVID-19 has already proved to be a formidable foe (Nadeem, 2020), especially for persons with disabilities. According to WHO, 15 per cent of the world's population (approximately one billion) are disabled in some way, many of whom are already familiar with the type of marginalization and social isolation that government decision-making has enforced on them and others worldwide. Suddenly, for the first time in a very long time, huge populations are coming face to face with a real sense of segregation and separation from normal life as individuals with the virus (along with those who live in their homes) are being forced to quarantine themselves in homes and hospitals. This feeling of isolation/segregation from normal life is common and not a temporary stage for many people, particularly for persons with disabilities.

Almost everyone will be temporarily or permanently disabled at some point in their lives, and those who live to old age often find it difficult to continue working (World Economic Forum, 2020). According to Agrawal (2020), "People with disabilities are not only among the most disadvantaged people in the developing world, but they are also among the most neglected." In India, alone, there are about 26.8 million people living with disabilities. The 2011 census shows that 10 per cent of households in India have at least one disabled member (Agrawal, 2020). Most of them live with their families and depend on them for basic needs, adding up to 25-30 million caregivers.

In far too many cases worldwide, the special needs of persons with disabilities are not being met. If we do not respond positively to the needs of persons with disabilities, we will fail to act in a humane fashion (Murthy, 2020). Even in the best of times, people with disabilities face difficulties in accessing health services due to unavailability, accessibility, affordability, stigma and discrimination. The risk of COVID-19 infection for persons with disabilities is increased by disruption of services and support, pre-health (underlying) conditions that increase the risk of developing severe ailments or dying, being excluded from health information and mainstream health provision, living in a world where accessibility is often limited and where barriers to goods and services are a challenge, and being disproportionately more likely to live in institutional settings (United Nations, 2020).

Issues and challenges faced by persons with disabilities and their caregivers

The COVID-19 pandemic has led to widespread ‘fear’, but one group (aside from the elderly) faces extra hazards and concerns, as well as anxieties: persons with disabilities, who are being deeply affected by the pandemic and associated social isolation in terms of food insecurity, access to health care and screening, medical decisions, and changes in work settings (e.g. working from home). The present crisis requires leadership at all levels of government, all sectors of civil society, and from persons with disabilities themselves (RespectAbility, 2020). Many people with disabilities cannot wash their hands properly without assistance from attendees/caregivers. In addition, the lack of toilets for persons with disabilities makes it difficult for them to ‘use the bathroom’ (Malhotra, 2020). Depending on the type of medication and insurance available – even in the absence of a global public health crisis – it can be difficult to get regular prescriptions refilled on time.

Some people with disabilities rely on the regular help and support of others to maintain their freedom (e.g. their ability to stay at home instead of nursing homes, group houses and other institutions). Due to the spread of contagious diseases, these services can get interrupted and overwhelmed. Helpers and caregivers may become ill themselves, forcing them to stay at home and disrupting services for people with disabilities (Pulrang, 2020). People with disabilities need personal hygiene help, which can be even more difficult if they are asked to wash their hands on their own. They may also need assistance taking a shower (Torres, 2020). Systems for a substitute caregiver, who is completely aware of the needs of an individual disabled person, need to be put in place until complete recovery of the usual caregiver (Jalali, Shahabi, Bagheri Lankarani, Kamali & Mojgani, 2020).

Some people with disabilities cannot detach themselves as effectively as others because they need constant and practical help from other people to carry out their daily activities. Physical disabilities, environmental barriers, or disruptions to services can make it very difficult for people with disabilities to clean homes and wash their hands frequently (Pulrang, 2020). This is especially acute in areas lacking basic infrastructure and adequate health services, such as on the Navajo Nation in the United States, which has extremely high per capita COVID-19 rates (Wyatte Grantham-Philips, 2020).

In several cases, the process of social isolation and social distancing is not possible for a person with a physical disability due to their dependence on others to meet their physical needs. It is unreasonable to expect a person with a developmental disability to cope when separated from their guardian (Malhotra, 2020). Persons with disabilities who cannot survive alone will not be able to follow government directed quarantine guidelines (Bernhard, 2020).

In some parts of the world, quarantine centers have come under severe criticism for not having proper lifts, toilets and other facilities for people with disabilities (Malhotra, 2020). The lack of availability of emergency related equipment, supplies of medications, nursing facilities, security, and other institutional obstructions pose major public health challenges to people with disabilities (Sharma, 2020). To make sure that persons with disabilities have access to information about COVID-19, this information should be made available in accessible formats.

Health-care structures must be physically accessible to persons with mobility, sensory and cognitive impairments. In addition, people with disabilities should not be barred from accessing health services in an emergency due to financial constraints or an existing problem (UN, 2020). Partially blind people rely on contact for most of their daily activities. To move, they must hold the hand of an escort and cannot read the messages that the rest of the population can see. They cannot practice social distancing unless they have innovative ways to maintain a safe distance using a white cane. And for persons with hearing loss – especially those who are unable to read, cannot hear messages and rely on lip reading – it becomes difficult for them to understand messages about COVID-19 (e.g. when and where to wear a mask). Media messages generally do not use sign language interpreters (Murthy, 2020).

For people with intellectual disabilities, isolating themselves and avoiding close contact with others is extremely difficult. Some (in group homes) are not able to change/alter life routines and find it impossible to understanding why they are being prohibited from engaging in social activities (e.g. meeting family members). In some countries, access to lifesaving treatment for people with COVID-19 is limited (Coaston, 2020). This situation is worse for persons with disabilities that face barriers to basic health care.

As we pass through the pandemic, people with disabilities are at significant risk, not only from the disease itself, but also from a disruption of services and routines that can cause it. As health experts and government officials emphasize the importance of maintaining a 6-foot distance to fight the virus, workers and families caring for people with disabilities face growing challenges that may be impossible to meet (Torres, 2020).

COVID-19 poses unique challenges to children with disabilities and to their parents and caregivers. For example, although social distancing has been widely promoted as the best strategy to avoid transmission, this advice may not be realistic for caregivers for children with disabilities and adolescents who need therapy or help with daily tasks (American Psychological Association, 2020). For many people, this means that the virus is interfering with regular visits to hospitals and rehabilitation centers for a variety of time-bound treatments (Malhotra, 2020).

Caregivers worry about the impact of isolation on children that have developmental disabilities – especially those with Down syndrome – because they may not get the treatment and therapies they need. The possible interruption of the development of children with disabilities (in large part due to draconian lockdown measures) has been widely discussed in the literature. In response, support networks have been established in many countries, with the goal of teaching ‘special needs’ children a variety of things, from how to grip a pencil to how to engage in social skills. The closure of schools because of COVID-19, which appears to be unwarranted at this point, is taxing both caregivers and children with disabilities, causing (perhaps) more harm than good. All of us should be worried about the pandemic's lasting, negative impact on the emotional and intellectual development of children (Dwyer, 2020), including those with disabilities.

Conclusion

People with disabilities, their families and caregivers are at significant risk of contracting COVID-19. It is critical that they have access to the information (information based on science and not politics) they need to take *appropriate precautions*. Lack of access to education for people with disabilities increases the risk of contracting and spreading the virus. Worldwide, the majority of people with disabilities are unemployed,

poor and live in large, overcrowded urban areas in the developing world. This increases the probability that they will become infected and restricts their capacity to respond to the epidemic in an appropriate way.

Funding or conflicts of interest statement: None of the authors have any relevant disclosures related to the funding of the project or any financial benefits received in relation to this research.

References

Adhikari, Meng, et al. (2020). “Epidemiology, causes, clinical manifestation and diagnosis, prevention and control of coronavirus disease (COVID-19) during the early outbreak period: a scoping review.” *Infectious Diseases of Poverty*, 9(1). Doi: 10.1186/s40249-020-00646-x

American Psychological Association (2020). Advice for caregivers of children with Disabilities in the era of COVID-19. [<https://www.apa.org/research/action/children-disabilities-COVID-19>, accessed April 17, 2020]

Bernhard, B. (2020). “Coronavirus Brings Added Worries For People With Disabilities”. [<https://www.disabilityscoop.com/2020/03/17/coronavirus-brings-added-worries-disabilities/27989/>, accessed, April 19, 2020]

Bhatia, I., & Azad, S. (2020). How COVID-19 lockdown has hit disabled people hard. *Times of India*. [<https://timesofindia.indiatimes.com/india/how-COVID-19-lockdown-has-hit-disabled-people-hard/articleshow/75003358.cms>, accessed April 16, 2020]

Brooks, Webster et al. (2020). “(2020). The Psychological Impact of Quarantine and How to Reduce It: Rapid Review of the Evidence”. *SSRN Electronic Journal*. Doi: 10.2139/ssrn.3532534

Cheke, Shinde et al. (2020). “Coronavirus: Hotspot on coronavirus disease 2019 in India.” *Indian J Med Sci*; 72(1):29-34.

Dwyer, D. (2020). “The other coronavirus front line: At home with special needs children: COVID-19 is a daunting challenge for families of children with disabilities”. [<https://abcnews.go.com/Politics/coronavirus-front-line-home-specialchildren/story?Id=69872230>, accessed April 19, 2020]

G.V.S, Murthy. (2020, April 12). People with disabilities have special issues during virus outbreak. *The Hindu*, [<https://www.thehindu.com/sci-tech/health/coronavirus-people-with-disabilities-have-special-issues-during-virus-outbreak-says-indian-indian-institute-of-public-health-chief-gvs-murthy/article31324294.ece>, accessed April 17, 2020]

Jalali, Shahabi et al. (2020). “COVID-19 and disabled people: perspectives from Iran”. *Disability & Society*, 1–4. doi:10.1080/09687599.2020.1754165

Malhotra, N. (2020). “Coronavirus: For People with Disabilities, avoiding COVID poses special challenges. [<https://scroll.in/article/956584/coronavirus-for-persons-with-disabilities-avoiding-COVID-19-poses-special-challenges>, accessed, April 19, 2020]

Maragakis, L.L. (2020). “Coronavirus, Social and Physical Distancing and Self-Quarantine”. [<https://www.hopkinsmedicine.org/health/conditions-and-diseases/coronavirus/coronavirus-social-distancing-and-self-quarantine/>, accessed June 17, 2020]

Nadeem, S. (2020). “Coronavirus COVID-19: Available Free Literature Provided by Various Companies, Journals, and Organizations around the World ”. *Journal of Ongoing Chemical Research*, 5(1), 7–13. doi: 10.5281/zenodo.3722904

Porta, Miquel, ed. (2008). Dictionary of Epidemiology. Oxford University Press. p. 179. ISBN 978-0-19-531449-6.

Pulrang, A. (2020). Things to Know about Coronavirus and People With disabilities: [<https://www.forbes.com/sites/andrewpulrang/2020/03/08/5-things-to-know-about-coronavirus-and-people-with-disabilities/>, accessed April 18, 2020]

RespectAbility (2020). People with Disabilities & the COVID-19 Pandemic: Key Issues & Resources: RespectAbility. [<https://www.respectability.org/2020/03/COVID-19-key-issues-resources/>, Accessed April 16, 2020]

Roy, B., & Mehrotra, S. (2020). COVID-19: Implications for the disabled. *The Hindu*. [<https://www.thehindubusinessline.com/profile/author/Baikunth-Roy-Santosh-Mehrotra-134457/>, accessed April 16, 2020]

Sharma, L. (2020) “Coronavirus: Why Persons with Disability Face a Crisis within a crisis”. [<https://livewire.thewire.in/rights/coronavirus-persons-with-disability/>, accessed April 19, 2020]

Torres, Ella. (2020). “Social distancing 'not possible' for people with disabilities, raising challenges: It is one of the many issues people with disabilities face amid the spread”. [<https://abcnews.go.com/Health/social-distancing-people-disabilities-raising-challenges/story?id=69486075>, accessed April 19, 2020]

UN (2020). Everyone included: Social impact of COVID-19. Department of Economic and Social Affairs Social Inclusion. United Nations. [<https://www.un.org/development/desa/dspd/everyone-included-COVID-19.html>, Accessed April 17, 2020]

UN (2020). Everyone included: Social impact of COVID-19. Department of Economic and Social Affairs Social Inclusion. United Nations. [<https://www.un.org/development/desa/dspd/everyone-included-COVID-19.html>, Accessed April 17, 2020]

WHO (2010). Emergencies, preparedness, Response: World Health Organization. [https://www.who.int/csr/disease/swineflu/frequently_asked_questions/pandemic/en/, accessed April 19, 2020]

WHO (2020). Coronavirus disease (COVID-19) outbreak. World Health Organization [https://www.who.int/health-topics/coronavirus#tab=tab_3, accessed April 19, 2020]

World Economic Forum (2020). COVID-19s isolated world is the norm for people with disabilities. [<https://www.weforum.org/agenda/2020/04/COVID-19-isolation-disabilities/> accessed April 17, 2020, World economic Forum, Switzerland]

Wyatte Grantham-Philips (2020). “On the Navajo Nation, COVID-19 death toll is higher than any US state. Here's how you can support community relief”. *USA Today*. [<https://www.usatoday.com/story/news/nation/2020/10/24/COVID-native-americans-how-to-help-navajo-nation/3652816001/>, accessed November 13, 2020]