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REVIEW ARTICLE

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Insights on COVID-19 and Disability: A Review of the Consideration of People with Disability in Communicating the Disease Profile and Interventions

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Abstract

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In the wake of the COVID-19 outbreak, governments and other key agencies have the responsibility of mainstreaming disability inclusion into pandemic responses to ensure that the rights and wellbeing of persons living with disabilities are safeguarded. While engaging with communities and larger populations in the response to COVID-19, it is important to understand the needs of specific groups that might experience barriers to accessing information, care and support or be at higher risk of exposure and secondary impact, such as children and adults with disabilities, who make up an estimated 15% of the population and are often invisible and excluded. We searched MEDLINE, PubMed, Google, Google scholar and LILACS and reference lists of eligible studies published January 2000–July 2020, reporting on disability challenges and COVID-19 communications to people living with disability. Persons Living with Disabilities are most likely to experience high negative impact on their day-to-day life needs due to the economic downturn brought about by the COVID-19 pandemic. There has to be deliberate undertaking to make COVID-19 related medical and quarantine policies and processes accessible and disability-inclusive. Apart from communicators of COVID-19 being inclusive in communicating the profile of the disease and interventions, there is a need to ensure that all pandemic responses are disability-inclusive, including through close consultation, meaningful participation and partnerships with persons with diverse disabilities.

Keywords: Covid-19; Coronavirus; Disability; Communication; People living with disabilities; Health information

Introduction

According to the World Health Organisation (WHO), there are more than 1.3 billion persons living with disabilities (PLWDs) worldwide. About 15-20 percent of the world's population are PLWD and they are no strangers to the kind of exclusion that coronavirus disease (COVID-19) has imposed on the rest. The 2019 coronavirus disease pandemic is likely to have a significant impact on such individuals, putting them at risk of increased morbidity and mortality, highlighting the urgent need for this population to have their rights to healthcare improved and maintaining the global commitment to universal health coverage by 2030 [1]. On the other hand, UNESCO recognizes that COVID-19's global influence has contributed to unprecedented difficulties affecting countries and all individuals across the globe. While there have been numerous efforts to share information with all people as a matter of urgency, there is limited, and in some situations, no information is given in accessible formats for PLWD. It is in compliance with the Convention on the Rights of Persons with Disabilities (CRPD), which calls on States Parties to take 'all necessary steps to ensure the health and protection of persons with disabilities in situations of risk' (Art. 11). To make the aforementioned worse, the proportion of PLWDs is much higher in third world countries, compared to the developed world. It has been established that COVID-19's effect is likely to be greater for people in lower socioeconomic groups that in countries with higher comprise PLWD globally [2].

Governments around the world are placing their citizens on various forms of interventions, including lockdowns, as the COVID-19 is increasingly gripping the global population. The United Nations (UN) Special Rapporteur on the Rights of PLWDs cautioned that little has been done to provide PLWDs with the advice and help required to protect them during the ongoing COVID-19 pandemic, as many of them are part of the high-risk community [3]. Many PLWDs depend on services that have been suspended and may not have enough money to stockpile food and medicines or afford the extra cost of home deliveries. Many PLWDs are poor and in vulnerable employment without adequate social protection. Data from the United Nations Economic and Social

Commission for Asia and the Pacific shows that the poverty rate gap between PLWDs and the general population can be as high as 20.6%. People living with disabilities are 2 to 6 times less likely to be working than non-disabled people. Any coping strategies, including social distancing and self-isolation, can be difficult as individuals with different disabilities will require varying help from personal assistants and communication workers to meet medical and everyday needs. People living with disabilities' livelihoods are now at significant risk due to the pandemic, especially those that may have underlying health problems. For example, people with amyotrophic lateral sclerosis experience degenerative functions in muscle strength and respiration; people with muscular dystrophy tend to have lower diaphragm function; and people with spinal cord injuries tend to have impaired lung function [4].

In the aftermath of the COVID-19 outbreak, policy makers are responsible for mainstreaming the integration of disability into pandemic responses to ensure that PLWD's rights and health are secured. UNESCO has taken concrete measures in this context to ensure that the rights of PLWD to access accurate information and contact on the pandemic are recognized. Therefore, UNESCO has made some videos in both the English and Sign languages, making them available to people with various forms of disabilities. The sign languages would also allow people in other countries to access the information as everyone else [5].

During the lockdown, as one of the immediate interventions that many governments across the globe have instituted, there is an immediate need to help PLWDs. This service can be given by supporting, securing and improving their rights. Caregivers can continue to help PLWDs access their social grants in countries where this is inevitable and do shopping during lockdown. People living with disabilities cannot be made to practice self-isolation or to deal with it on their own. For example, to those with Attention Deficit Hyperactivity Disorder, being indoors is a nightmare. For many other purposes, most people in different cultures need some kind of medical help, other forms of health care, and the regular visits to rehabilitation centers [5].

While much is not known about COVID - 19, it is, however, not known how vulnerable populations like PLWDs might be affected by pandemics. We recognize that many developing countries do not have the surveillance systems, health services and health infrastructure to respond in such a way as to slow down the impact of COVID - 19's communities. We also recognize that there are disadvantaged groups, such as: the elderly, those with disabilities, people in prison and other broad spectrums, and thus this analysis is aimed at providing insights into the profile of COVID-19 and other intervention and how such is being communicated to PLWD.

Materials and Methods

A systematic search was performed on the databases MEDLINE, PubMed, LILACS, and Google Scholar. Each of the 4 sites used a similar search technique. The subject headings used by MeSH included COVID-19 and Impairment, as well as Communication. Finally, in addition to filters for the date, the presence of an abstract and the English language, the following technique was used to search MEDLINE, based on MeSH and Major Topics: (((“COVID-19 related disability/disease profile, prevention and control” [Mesh] OR “COVID-19 /communicating the disease” [Mesh])) OR “Disability/Infectious disease communication” and for google search, PubMed and LILACS “COVID-19 and communication to PLWDs” OR (“COVID-19 versus Disability” OR “COVID-19” OR “COVID-19 and Communication to vulnerable people”))) AND (“Communicating COVID-19 and Disability”) for google scholar. This search yielded 79 articles and other online documents that were reviewed first by reading the abstracts. Seventeen were eliminated as inappropriate for the purposes of the study. Finally, a total of 68 articles were included.

The search in LILACS was based on locators and descriptor categories: Basically: COVID-19 communication among PLWD. English, Spanish, and Portuguese. The articles retrieved in MEDLINE (14) were filtered out, leaving 4 manuscripts that were included in the study.

In addition, we reviewed 10 more articles retrieved using Related citations in PubMed and LILACS with 4 articles while 50 articles from Google scholar and Google. A total of 68 articles were reviewed (PubMed 10, 4 LILACS,

4 MEDLINE and 50 Google scholar and Google). Twenty articles were excluded for not providing specific data on COVID-19 and disability.

The following parameters were extracted after selecting the literature: region, year of publication, impairment, and Communications COVID-19, impairment, and challenges. The data was clustered in the most homogeneous way possible. Observations from the discussion section were derived from papers considered interesting or novel, and the approach used by the authors was rated from 1 to 3 to measure the content of the publications. The articles were grouped by geographic and cultural regions: North America (US and Canada), Latin America, Europe, Africa.

Results and Discussion

Impact of COVID-19 on the Lives of PWDs Persons Living with Disabilities are most likely to experience high negative impact on their day-to-day life needs due to the economic downturn brought about by the COVID-19 pandemic (UNHR, 2020). The United Nations Human Rights (2020) states that it is a requirement for governments to “make information available in readily understandable formats and languages, including indigenous languages, ethnic and religious minorities, and adapting information for people with specific needs, including the visually- and hearing-impaired, and reaching those with limited or no ability to read or with no internet access”. People including PLWD have a right to participate in decision-making that affects their lives especially at this critical time of COVID-19 pandemic. Internet, television and radio are channels mostly used to receive information for the majority of populations especially in low and middle income countries. In developed countries, other means such as high technical phones which operate almost like a computer have all the necessary information which people can access.

Because of the high risk which PLWD are likely to experience, WHO, (2020a). Unfortunately, in most low income countries PLWD and a larger group of the population may not afford to possess a high tech phone to get the information on COVI-19. According to the United Nations Convention for the Rights of Persons with Disabilities, (UNCRPD, 2006), Human Rights Watch (HRW, 2020), the UNCRPD contains 50 Articles which pertain to

the rights and fundamental freedoms which PLWD are endowed with and are expected to experience and enjoy life like any other person. In the convention on the Rights of Persons with Disabilities – Articles, there are fifty articles addressing various needs for PLWD. Articles 5 to 30 are the articles which describe the rights which PLWD should enjoy.

The Impact of denying PLWD getting or being

Article 8: Awareness Raising

Article 9: Accessibility

Article 11: Situation of risk and humanitarian emergencies

Article 21: Freedom of expression and opinion, and access to information

Article 25 – Health

Actions to be taken

1. Governments and all stakeholders

2. PLWD Themselves

availed the correct and adequate information on COVID-19 particularly on the prevention and protection from contracting the infection will be in the following ways as existing on selected convention on the Rights of Persons with Disabilities – Articles including the actions to be taken by key players around the COVID-19 outbreak;

- Less or no information about COVID-19 is availed to PLWD, particularly persons with visual impairment.
- No materials are printed in brail for PLW visual impairment to read; for example, in Zambia
- Risk of majority of PLWD being ignorant of the appropriate measures needed to prevent contracting the disease (Thelwall & Levitt, 2020)
- Most buildings and build environment have no signage particularly in low income countries such as Zambia to guide the safe movement of PLWD
- The inaccessible transport in most low-income countries pose a huge risk for PLWD who need assistance all the time, for movement and conducting any such life activities.
- This removes completely the social distance requirement between one another (WHO, 2020a-Global Guidelines to reduce or prevent spread of COVID-19) among PLWD
- Covid-19 is a risk disease for everyone, worse still for PLWD (WHO, 2020a; Thelwall & Levitt 2020)
- WHO (2020a) has developed guidelines as special considerations for PLWD to be actioned by nations
- PLWD have their own opinion, social, health, economic and development needs which they may need to communicate on their own or in their own mode or model of communication.
- However, society usually may not provide that platform to avail the opportunity for PLWD to do so (WHO, 2020a; Thelwall and Levitt 2020)
- It is very clear that normal health care services have been disrupted globally with government focusing on COVID-19 apportioning additional resources towards COVID-19 activities
- However, this disruption in the systems, may disproportionately impacting negatively on the health care needs for PLWD (WHO, 2020a)
- Governments, public and private institutions and companies must take appropriate actions to reduce the barriers experienced by PLWD
- Use of all means of information dissemination to all parts of the country and all levels of society
- PLWD and their households should to follow WHO, (2020a) Guidelines on prevention and protection from contracting COVID-19
- Avoid crowding environments, reducing visiting the shops frequently
- Consider gathering essential items such as food, groceries, medications and for paying for utility services
- Work from home
- Ensure assistive devices needed to enhance function are in good working order to avoid visiting public places often
- Ensure you have emergency telephone numbers; for the police, hospital and close family/friends who could heal in the shortest time in-case you need help
- All the members of your household must know the same and correct information about COVID-19, what to do if one person contracted the disease
- Ensure that you listen to any official news and reports or updates on the current events and any new information which might inform you of any new actions to be taken.
- Disability organizations must take a lead in ensuring that all necessary information is evenly distributed to PLWD especially those living in rural areas where media of television, radio and/or telephone platforms may not be adequately available in remote areas particularly in low income countries

PLWDs and Access to COVID-19 Information and Interventions Modifications

Access to information also constitutes an obstacle for PWD which has unique communication needs. They are often removed from decision-making spaces and have limited

access to information about outbreaks and service availability. In this COVID-19 era, PLWD are more exposed to barriers that put them at a higher risk of infection. Some are unable to maintain basic hygiene due to their disability, such as hand washing, and face difficulties in creating social distances because they require help from other people. Others require tactile feedback to get knowledge from

the world or to help them physically. Many PLWD have reported difficulties in accessing information on public health and health care, as well as disruptions to the services they depend on which has made them more vulnerable [6].

The need to modify the interventions is therefore necessary when engaging in the response to COVID-19 with communities and broader populations, it is important to consider the needs of particular groups who may face barriers to accessing knowledge, care and support or may be at higher risk of exposure and secondary impacts, such as children and adults with disabilities, who make up an estimated 15% of the population and are often invisible. Disability organizations can provide valuable advice and support on accessibility of information, and help develop local capacity for handicap-including emergency preparedness and response [7].

The COVID-19 crisis is new. It demands that we all behave, connect and communicate differently than we are used to. The social inequalities which exacerbate the impact of COVID-19 on PLWD are not new, however. The danger in responding to the current crisis is that PLWD will again be left behind. The good thing is that we already know what works. Social justice, successful inclusion, equality of opportunity and fair work are important. Any correspondence on COVID-19 relating to public health, education and employment, including telework arrangements, must be accessible to PLWDs, including through the use of sign language, subtitles and open websites. Contact should also discuss the relevant PLWDs' situation [8]. There is need to disseminate information that uses clear and simple language. Provide information in accessible formats, like braille, large print. The need to offer multiple forms of communication should be reemphasized, such as text captioning or signed videos, text captioning for hearing impaired, online materials for people who use assistive technology. Involvement of organizations of PLWD in consultation and decision making may this achievable. The ultimate goal is to provide tailored interventions to meet individual needs and other social support networks [5].

Above anything else, in the current situation of the global health crisis due to COVID-19, from Bridging the Gap we would like to emphasize the higher risk faced by PLWD or chronic illnesses, especially in low

and middle-income countries. In order to successfully meet this challenge and comply with the 2030 Agenda, PLWD must be included in all plans to manage the current COVID-19 outbreak. This implies that the information provided by governments and institutions both to prevent infection and how to act in case of illness must be available in accessible formats as earlier mentioned including use of alternative text in images and graphics displayed digitally, and easy-to-read versions.

COVID-19 mitigation strategies must be inclusive of PLWD to ensure they maintain respect for “dignity, human rights and fundamental freedoms,”⁵ and avoid widening existing disparities. This necessitates accelerating efforts to include these groups in preparedness and response planning, and requires diligence, creativity, and innovative thinking, to preserve our commitment to UHC, and ensure PLWD are not forgotten [9].

Challenges of PWD During the COVID-19 Outbreak

For PLWD, there are barriers to social distancing and taking other preventative measures during the pandemic that put them at higher risk for getting sick. Some can't isolate as much as other people because they need “regular, hands-on help from other people to do every day self-care tasks,” Tasks such as getting groceries can be difficult for PLWD because some rely on others for transportation and shopping, Forbes reported. Handwashing can even be cumbersome due to “physical impairments, environmental barriers, or interrupted services. The Centers for Disease Control and Prevention's guidance said PLWD who are most at risk are those with limited mobility or have to have close contact with family members and care providers, who have difficulty understanding or practicing preventative measures including hand washing and social distancing, and who have a hard time communicating the symptoms of the illness [5].

Some of the PLWD may often have underlying health conditions which make them more vulnerable to get infected by COVID-19. Considering the current lockdown situations in most parts of the world, The National Domestic Workers Alliance, an advocacy organization promoting the rights of domestic workers in the United States did different consultations with different groups of PLWD throughout the USA.

Through these consultations, it was found that the PLWD and their family members who are in extremely vulnerable conditions are badly affected for their daily lives [10,11].

Some PLWD who were running small groceries for their daily lives as income generative activities have been stopped. Persons with spinal cord injuries are facing big health challenges due to the unavailability of their daily medical kits and clinical apparatus like clean intermittent catheterization that they do specifically need for everyday lives. Persons who have hemophilia are in great danger of not getting the factor that they require. Similarly, the girls and women with disabilities who have spinal cord injuries or are wheelchair users are getting their health worse due to the continuous bed rest at home due to lockdown. And, this is resulting in body swelling, urinary tract infection, and infection in the backbone [12].

Persons who do not have their mobility always need a personal assistant for their daily lives. Due to the lockdown situation, PLWD are confined at their own home because of which they are not able to purchase their daily needs like diapers, sanitary pads, hygiene materials on their own. Persons with intellectual disabilities are also lacking the sanitary and hygiene stuff to get safe from infection in this situation. Many PLWD are now facing mental stress and anxiety due to this pandemic [13].

Inclusiveness of COVID-19 Pandemic Response

There is a need to ensure that all pandemic responses are disability-inclusive, including through close consultation, meaningful participation and partnerships with persons with diverse disabilities. All policy responses to COVID-19 should be disability-inclusive, ranging from public health and containment measures to economic stimulus packages and socioeconomic impact assessments. Given the diverse range of disabilities and their respective specificities, there is a need for governments to consult organizations of PLWD throughout the process of policy design and implementation to ensure the needs of persons with diverse disabilities are adequately met, with their rights and dignity respectfully upheld [13,14].

There has to be deliberate undertaking to make COVID-19 related medical and

quarantine policies and processes accessible and disability-inclusive. There is a need to make sure that designated health facilities such as testing and quarantine centres are accessible so as to allow PLWD to seek medical assistance when required. Medical providers need to stand ready to offer sign language interpretation, including exploring the use of relay services and/or remote signing via smartphone applications and video technologies. Where required, governments should allocate trained personal assistants to address the daily needs of PLWD in quarantine; medical and social service professionals should also stand ready to support their emotional and mental wellbeing during the confinement, especially for those with psychosocial and/or intellectual disabilities. Throughout the process, the attitudes of healthcare professionals should be respectful and non-discriminatory – and all unlawful seclusion, restraints, non-consensual medication should be strictly prohibited [15,16].

It is really a tough time particularly those PLWD. We are safe and protected through lockdowns. However, this is difficult for the people living in institutional settings such as hostels, group accommodation and sharing compartments. PLWD are much deprived of protective materials and hygiene such as hand sanitizers, face masks, soaps and paper towels. The other concern is that adequate information is inaccessible, and easy to read text unavailable and for most of the countries, there is no sign-language captioning in TV news. Because of the lockdown situation in many countries, there is a lack of adequate food stuff. There is no particular attention to PLWD in the isolation centers since they are at high risk of COVID-19 infection [17, 18]. Most of the PLWD living in isolation their hands are being exposed for touching surfaces and communication, such as rolling a wheelchair. PLWD and their representing organizations are doing their level best to influence the Government by submitting a petition to include concerns of PLWD in the Government scheme and information system. One of the organizations called Abilis Foundation has indicated that there is a need to provide information accessible and easy for example Abilis Foundation has developed accessible “Information Education and Communication” materials for Deaf and other cognitive disabilities. While the International Disability Alliance has provided some

recommendations toward a Disability-Inclusive COVID19 Response and the key recommendations include:

1. Persons with disabilities must receive information about infection mitigating tips, public restriction plans, and the services offered, in a diversity of accessible formats with use of accessible technologies
2. Additional protective measures must be taken for people with certain types of impairment
3. Rapid awareness raising and training of personnel involved in the response are Essential
4. All preparedness and response plans must be inclusive of and accessible to women with disabilities
5. No disability-based institutionalization and abandonment is acceptable
6. During quarantine, support services, personal assistance, physical and communication accessibility must be ensured
7. Measures of public restrictions must consider persons with disabilities on an equal basis with others
8. Persons with disabilities in need of health services due to COVID19 cannot be deprioritized on grounds of their disability
9. OPDs can and should play a key role in raising awareness of persons with disabilities and their families.
10. OPDs can and should play a key role in advocating for disability-inclusive response to the COVID19 crisis. (UNESCO, COVID-19 response (2020; UNHR, 2020)

Conclusion

Based on the various literature utilized in this review, it is clear that PLWD have not been fully included in the activities concerning prevention of COVID-19 globally. Governments across the globe have instituted various measures to prevent the human-to-human spread of COVID-19. However, the question still remains; how much have PLWD been involved in the development and dissemination of information concerning COVID-19 to all sectors of society around the world? This concern cuts across all levels of

development of various countries around the world on all type of messages and the mode of dissemination of these messages and who disseminates these messages has not favored PLWD. Based on that view point, global organizations such as WHO, Human Rights Watch, International Disability Alliance and the United Nations Department of Economic and Social Affairs on Disability have developed guidelines and recommendations for governments, civil society, private and public sector institutions including PLWD organizations to utilize. Therefore, different governments across the world will need to deliberately leverage on this and be inclusive in communicating COVID-19 profiles and interventions for PLWD. This action is needed to improve the development, dissemination and use of information and messages for PLWD. It is therefore, hoped that these guidelines and recommendations will be fully utilized by government and all stakeholders to enhance inclusion of PLWD in the fight against COVID-19 and reduce the negative impact which this infectious disease has already caused to the human race across the globe.

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Author contributions

BC contributed to the study design and collected data. BC, MCB, MMS, CK, PDP and GM analysed articles obtained. HS and BC sourced and reviewed relevant literature. BC, MCB, MMS, CK, PDP, GM wrote and also reviewed the manuscript for important intellectual content. All authors reviewed the final manuscript and approved it before submission.

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