Challenges in Implementing Health Protocols of COVID-19 for People with Vision Loss

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Keywords:

COVID-19, vision loss, challenges, protocols, accessibility; *COVID-19*; *disabilitas visual*; *tantangan*; *protokol*; *aksesibilitas*

Abstract

COVID-19 has caused tremendous challenges for people with disabilities, such as those with vision loss, which affect their daily lives. This qualitative study was undertaken on six participants with vision loss to understand the challenges they had when implementing health protocols in the prevention of COVID-19. Open coding, axial coding, and selective coding were conducted to analyse the data. The study also pointed out that participants experienced physical, psychological, economic and social challenges in exercising the health protocols of COVID-19, such as in implementing physical distancing and wearing face masks. The participants felt alienated because of their limited direct interactions and experienced loss of income. Online learning caused minimize learning experiences and accessibility problems. These challenges potentially widen discrimination and inequality practices for people with disabilities in Indonesia with COVID-19 mitigation preparedness plan.

COVID-19 telah menimbulkan tantangan bagi penyandang disabilitas, termasuk mereka dengan hambatan visual, yang mempengaruhi kehidupan mereka sehari-hari. Penelitian ini merupakan studi kualitatif yang bertujuan untuk memahami tantangan dan strategi yang dilakukan partisipan dengan hambatan visual berkaitan dengan melaksanakan kebijakan protokol kesehatan. Open coding, axial coding, dan selective coding dilakukan untuk menganalisis data. Hasil penelitian menunjukkan bahwa partisipan mengalami tantangan fisik, psikologis, sosial, dan ekonomi selama menjalankan protokol kesehatan COVID-19, yang meliputi penggunaan masker dan menjaga jarak. Partisipan menilai adanya pembatasan sosial menimbulkan perasaan terasing karena interaksi tidak dapat dilakukan secara leluasa dan berkurangnya bahkan hilangnya pendapatan. Pembelajaran online mengakibatkan terbatasnya pengalaman belajar dan akses terhadap materi pembelajaran. Tantangan ini berpotensi memperkuat praktik diskriminasi, yang telah terjadi sebelumnya sehingga semakin memperlebar praktik eksklusi bagi penyandang disabilitas di Indonesia, terutama berkaitan dengan manajemen mitigasi penanganan bencana COVID-19.

Journal of Disability Studies
INKLUSI
Vol. 09, No. 01, 2022
10.14421/ijds.090104
Submitted: 17 Des 2021

Accepted: 24 Juni 2022

A. Introduction

Since the first announcement of confirmed COVID-19 cases in early March 2020, the number of confirmed cases has continued to increase (Mukaromah, 2020). The government has implemented some policies to control the spreading of COVID-19 virus such as the implementation of physical distancing, large-scale social restrictions to trace the confirmed cases and isolation policies in provinces and regions that implement large-scale social restrictions (World Health Organization Indonesia, 2020). COVID-19 was declared in early 2020 as one of the diseases causing the pandemic (Taylor, 2019). A pandemic is a large-scale epidemic that affects millions of individuals in several countries and spreads throughout the world (World Health Organization Indonesia, 2020). The cause of a pandemic is a group of emerging infectious diseases, including newly identified pathogens that re-emerge. Pandemic conditions as of October 15, 2021, as many as 4,233,014 people were confirmed positive for COVID-19 with a cumulative cure rate of 96,2%. Five out of 34 provinces reach the highest patient recovery rate daily (Tim Komunikasi Komite Penanganan COVID-19, 2021).

The number of COVID-19 confirmed cases since July 2021 has increased so that the Indonesian government decided to implement the policy of Community Activities Restrictions Enforcement or PPKM to control the transmission of COVID-19 (Kementerian Koordinator Bidang Perekonomian, 2021). The implementation of the PPKM is reviewed periodically based on the conditions in each region in Indonesia (KOMINFO, 2021). The Indonesian government has also mentioned that the COVID-19 pandemic is a national disaster that causes both death and loss in various aspects of life, showing that no certain community group is excluded from the risk of being exposed to COVID-19, including people with disabilities.

A number of studies have shown that people with disabilities are one of the social groups that are worst affected by the COVID-19 pandemic (Brooks et al., 2020; Kuper et al., 2020; Luo et al., 2020; McKinney et al., 2020). For example, a study by McKinney et al provided some evidence of challenges experienced by people with disabilities during the pandemic (McKinney et al., 2020). Issues related to access to healthcare and services and minimum knowledge of professionals to interact and communicate heighten the risks of people with disabilities not receiving appropriate care.

These studies demonstrate that COVID-19 raises a concern on how rights of people with disabilities are potentially violated, even prior to the pandemic. As a result, they are considered as a community group that has the potential to transmit the COVID-19 virus (Boyle et al., 2020; Jumreornvong et al., 2020; McKinney et al., 2020). Interestingly, the efforts to control the spread of COVID-19 taken by the government have not included persons with disabilities as a community group in mitigation strategies for COVID-19 (Murray, 2011; Peek & Stough, 2010; Smith et al., 2012).

The urgency to include people with disabilities in disaster mitigation strategies has been shown from previous studies, although they are particularly applied in natural disaster settings (Raja & Narasimhan, 2013; Ronoh et al., 2015). The findings demonstrate that people with disabilities are often neglected in disaster-related initiatives or efforts. As a result, the needs and rights of people with disabilities might be abandoned and violated. Similarly, the COVID-19 pandemic can also be classified as a disaster because of its characteristics that may create uncertainty and a sense of urgency which potentially disrupt their lives. However, limited studies within the Indonesian setting have documented people with disabilities' challenges in response to health protocol measures. Systematic and inclusive-responsive actions should be put in place as people with disabilities are vulnerable to disasters and prone to experiencing discrimination and challenges during the pandemic situations (Australian Health Sector Emergency Response Plan for Novel Coronavirus (Covid-19), 2020). The growing stigma about people with disabilities resulting in barriers for them to access public services and conduct activities in the public spaces during the COVID-19 pandemic. For example, the COVID-19 tracing application initiated by the Ministry of Information and Technology does not provide features that take into account the rights of persons with disabilities to accessible information, such as sign language or braille features. The COVID-19 pandemic has affected people with disabilities to become increasingly dependent on others to meet their daily needs. Government policies relating to the handling of COVID-19 as stated in the Decree of Minister of Health Number HK.01.07/Menkes/382/2020 on Health Protocols for the People in Public Places and Facilities require a minimum distance of one meter from other people to prevent others from being exposed to the risk of infection transmitted from droplets from people (Kementerian Kesehatan RI, 2020, p. 7). The 3M health protocol which was later developed into 5M, namely wearing masks, washing hands, maintaining distance, avoiding crowds, and reducing mobility, are expected to reduce the spread and transmission of COVID-19.

This policy however, can be a challenge for people with vision loss considering that they experience barriers in orientation and mobility which result in them being dependent on others, making it difficult to implement health protocols related to social distancing. As a result, people with vision loss are considered to be at high risk of spreading or contracting the COVID-19 virus. Lack of studies on the challenges experienced by people with vision loss in implementing the COVID-19 health protocol shows that COVID-19 prevention policies cannot be applied to some people with disabilities if they do not accommodate their needs and conditions. The purpose of this study is to understand the challenges experienced by people with vision loss during the implementation of the COVID-19 health protocol. An understanding of their challenges related to the management of the COVID-19 pandemic disaster mitigation policy will encourage more participatory efforts by involving persons with disabilities as an integral part of society to ensure that their rights are fulfilled, such as the right of accessibility and protection in risky and emergency situations, as stated in Law No. 19 Year 2011 (President of Republic of Indonesia) in the management of handling COVID-19 as a disability-inclusive COVID-19 response. The significance of this study is to gain understanding of challenges from the perspectives of people with vision loss when applying health protocols during the COVID-19 pandemic. It is expected that this study can provide a better understanding of what needs to be improved in the health protection measures, so that their health and wellbeing are taken into account during the crisis situation.

B. Research Question

Based on this description, the research questions to be answered in this study is: What are the challenges experienced by people with vision loss in implementing health protocols during the COVID-19 pandemic?

C. Literature Review

A pandemic is a large-scale epidemic that affects millions of individuals in several countries and spreads throughout the world (World Health Organization Indonesia, 2020). A pandemic is caused by a group of emerging infectious diseases, including newly identified pathogens that re-emerge. COVID-19 was declared in early 2020 as one of the diseases that cause the current pandemic (Taylor, 2019). Pandemics are often characterized by uncertainty, confusion and emergency responses. Uncertainty includes the chance of being infected and the levels of infections, misinformation spread in the community, ways to handle it, and the duration of the pandemic stops (Kanadiya & Sallar, 2011), all of which can contribute to distress (Neria & Sullivan, 2011) and trigger anxiety.

When the pandemic has just started, many are not affected by their mental health, but when there are prolonged physical restrictions, access limitations, and declined financial conditions, many cases of anxiety, depression and somatic complaints are reported, in addition to conflicts within the family or between communities. Taylor states that the psychological effects of a pandemic are becoming more noticeable, broader, and longer than the infectious effects of the disease itself (Taylor, 2019). As a result, individuals consciously ignore health protocols, including staying in crowds, not wearing masks (Lilleholt et al., 2020), getting exhausted and offended easily (Zerbe, 2020).

Due to the nature of disabilities, applying health protocols during the COVID-19 pandemic can be a challenge for some people with disabilities (Boyle et al., 2020).

For those who need assistance from their carers or support workers, the COVID-19 pandemic seems to intensify their reliance on others to meet their needs, often on a daily basis. They may experience difficulties in maintaining social distancing or communicating symptoms, resulting in delays of diagnosis and care. The presence of challenges during the COVID-19 shows how health protocols may not address the needs of people with disabilities. In fact, people with disabilities are prone to experiencing neglect, abuse, and discrimination during the COVID-19 pandemic. The consequences of neglect and abuse may be unintentional; however, these can have significant impacts on whether their rights are taken into account and people with disabilities should be viewed as individuals who are capable of participating actively in disaster risk planning and programs (Australian Human Rights Commission, 2020).

Although several strategies for dealing with COVID-19 have become challenges for people with disabilities, the strategies seem to overlook people with vision loss (Mulibana, 2020). Several challenges for implementing the health protocols include feeling discomforts for people with vision loss, including psychological distress and disorders (Brooks et al., 2020), financial constraints, risks of losing income and job, and inadequate accessibility to education, health information and environments. Accessibility issues become prominent to ensure that the information on the virus is communicated and updated in an accessible manner. For example, the COVID-19 information should be presented in formats that meet the needs of people with vision loss, such as Braille.

It is estimated that one percent of people with vision loss in Indonesia (https://pertuni.or.id) depend on information presented in Braille format, larger print sizes, as well as speaking books or voice recordings. Such issues may eventually influence how people with vision loss adhere to the COVID-19 related prevention actions (Australian Health Sector Emergency Response Plan for Novel Coronavirus (Covid-19), 2020). People with vision loss also experience challenges related to mobility orientation. People with vision loss are difficult to estimate their range of motion, dangers or threats. They will be able to measure the danger that might occur as long as it can be identified by the hands, feet, ears or nose (Somantri, 2007).

Furthermore, the limitations to recognize the surrounding stimuli make it difficult for people with vision loss to respond appropriately. As a result, they have the potential to experience anxiety or feeling worried as a result of their inability to respond appropriately, predict and anticipate the possibilities that occur in their environment.

D. Methodology

1. Research Design

Understanding challenges faced by people with vision loss requires in-depth inquiry. A phenomenological qualitative design was performed for this study. Some important issues related to how people with vision loss dealt with COVID-19 are still limitedly understood within the Indonesian context, which justified the use of qualitative approach. Thus, through the qualitative approach, the authors gain rich insight and nuance for understanding on how people with vision loss make meaning for their experiences during the COVID-19 pandemic.

2. Participants

The authors had access to meet the leader of a community of people with vision loss who personally agreed to join the study. The leader helped the researchers to get in touch with five other potential subjects, who voluntarily participated in this study after receiving further explanation about the study from the researchers. In the end, a total of six participants were involved in this study. Informed consent was obtained prior to data collection. All participants were between 18 – 50 years old and they had vision loss.

3. Data collection

Semi structured interviews and focus group discussion were applied to obtain the information related to challenges experienced by the participants during the implementation of COVID-19 protocols. Open-ended questions were conducted to allow participants to express their feelings and concerns about their lives. Both interviews and discussions were audio-recorded when the participants gave permissions.

4. Data analysis

Deductive and inductive approaches were utilized because they provided a comprehensive approach by engaging in detailed readings of the raw data to produce themes and subthemes also using pre-existing concepts to capture important information, which was applied to the data (Azungah, 2018). The interviews were transcribed and analysed manually via open, axial, and selective coding. Open coding was initiated by categorizing the data into segments and interpreting them. Relevant labels were created and assigned to each sentence or phrase, and were grouped as needed. An axial coding was applied by regrouping and linking themes into each other logically. A selective coding was performed by selecting a primary theme and then related the primary theme to other themes appropriately.

E. Findings and Discussions

Table 1.
Characteristics of the subjects

Initials	Sex	Age
Eka	Male	20
Bayu	Male	50
Wahyu	Male	42
Dian	Female	18
Anis	Female	18
Heni	Female	19

Findings of this article focused on two themes that emerged from the subjects as presented in Table 2 below.

Table 2.
Themes and Sub-themes

Themes	Sub-themes
Challenges	Physical discomfort Touching is unavoidable Economic hardships Inaccessible information Limited interactions
Impacts	Being invisible Exercising more efforts

1. Challenges

a. Physical discomfort

All subjects understand and implement health protocols from the government in the prevention of COVID-19. For instance, Eka stated:

> wearing masks when traveling, [implementing] social distancing ...I rarely travel... to avoid groups of people...washing my hands. (I1, Eka, 19-26)

They mentioned that the protocols had to be followed to minimise the spread of the COVID-19. They realised that the protocols might “limit” their daily lives as they could not leave their homes, which affected their physical condition. For example, Anis stated that during the lockdown, she “felt dizzy easily” as she mentioned that she hardly never left her home. A study by Sahin et al. (2021) pointed out that headache was one of the most frequent pains reported during COVID-19. Further study should be undertaken to investigate this finding in more detail to find out whether her headache affected her quality of life daily and strategies she applied in managing her condition.

Eka and Wahyu stated that the use of masks caused discomfort. Eka said that wearing a mask made him feel “stuffy” while Wahyu said he was “coughing and gasping for air” when wearing a mask because the mask did not allow them to breathe and speak freely. This finding supported a previous study that mask wearing was associated with perceived respiratory problems, such as shortness of breath (Scheid et al., 2020).

b. Touching is unavoidable

Regarding the implementation of physical distancing, three subjects who has vision loss stated that there were having some difficulties when doing social distancing, as stated below:

> Implementing social distancing is indeed a bit difficult, yes, for people with vision loss. Holding hands. (Bayu, 123-125).
>
> It is difficult to maintain social distancing. (Wahyu, 141)
>
> Social distancing shouldn’t be implemented by people with vision loss, it’s difficult to be put into actions. (Eka, 145-146)

Physical distancing can be challenging for people with vision loss as they are constrained for only being able to experience the environment through touch (Suraweera et al., 2021) which affects their mobility. For example, three subjects in this study explained that physical distancing policy was difficult to implement, especially when they gathered. Eka reiterated the problems associated with the implementation of physical distancing, thus “it is impossible not to touch”. Further, Bayu highlighted that for people with vision loss “we don’t have other options except touching each other”. In a world where the majority of people receive information and explore their surroundings using visual modality, people with vision loss only rely on other sensory modalities, such as touch to direct and inform what they have to do. For these subjects, physical distancing was perceived as an awkward experience as they could not estimate what kind of situation they were in, which might become a barrier for them in running their daily lives.

c. Economic hardships

Physical distancing was also disproportionately believed to disrupt the economic lives of people with vision loss. In this study, three subjects shared their experiences and their peers’ stories who were no longer working in areas that require physical contacts, such as giving massages. The majority of people with vision loss relied on working in the informal sectors. As they did not have alternative income sources, that posed a financial burden when COVID-19 shutdown took place. According to the report released by *Jaringan Organisasi Penyandang Disabilitas untuk Respons Covid-19* with MAHKOTA (Satriana, 2020), the majority of people with disabilities were at higher risk of experiencing economic challenges, such as being unemployed, and having low and uncertain income, which may cause them to be categorized as poor (Satriana, 2020; Suraweera et al., 2021).

d. Inaccessible information

Bayu stated that, compared to other people with disabilities, people with vision loss are treated unfairly with regard to the accessibility of information, considering that not all people with vision loss can read Braille, especially those who have recently lost their sight and need some adjustments to read Braille, as Bayu explained:

> When talking about policy…information in Braille may be available, but we don't have enough information regarding the location, the availability of buttons in Braille, and some people with vision loss can't read Braille … (I2, Bayu, 170-173).

In addition, Bayu highlighted the difficulty for people with vision loss to access information presented in the form of images rather than text. He complained that people with vision loss often received information in the form of pictures. As a result, they cannot obtain the information well. Furthermore, he said that text-based information would be more readable or listened to through a screen reader than an application installed on the phone.

> For sure we use some applications to assist us, but some of them are not compatible. (I2, Bayu, 187)

Failure in providing accessible information for people with vision loss results in their difficulties to obtain updated information, such as the management of handling COVID -19. Lack of accessible information may then pose people with vision loss, not only put them in higher risk of infection, but reinforce discrimination and barriers to information, education, social services, health care, and social inclusion (Jumreornvong et al., 2020). When comparing with other disabilities, accessible information for the Deaf and intellectual disabilities have been put in place. For example, in the UK, Association for Deaf People gives information about COVID-19 in sign language (Royal Association for Deaf People, 2020), or in a simple format for people with intellectual disabilities (Mencap, 2020).

e. Limited interactions

All subjects in this study mentioned that during the COVID-19 pandemic they did not interact with their peers face-to-face. For example, Anis expressed that her social life was “limited and stuck”. They felt a loss of connectivity with their peers. This finding was in accordance with Kim and Florack (2021) who found that restricted social interaction could decrease the level of well-being. However, they realised that social media, such as WhatsApp could help them to minimise their loneliness. They also said that making a call to keep in touch with each other was important to help them cope with the COVID-19 restrictions. This finding demonstrated that maintaining social connection with friends was imperative for people with vision loss to gain social support that potentially decreased negative psychological consequences from engaging in active social interactions (Kim & Florack, 2021).

2. Impacts

a. Being invisible

The COVID-19 protocols require a limitation of any activities that pose risk of contracting the virus, such as gatherings. As a result, a school closure policy is taken, and learning is made online. According to Eka, online learning created frustration and tension as he had to adapt with the use of various learning platforms that were not always accessible for him, as stated below:

> online learning ... requires individual tasks ... the assignments and my understanding on the materials are more challenging, adapting to the applications is also difficult. (I1, Eka, 7, 9-10)

The obstacles faced by Eka in finishing the tasks given by the lecturers were related to the difficulty of finding the references and the lack of understanding of the material being taught. Furthermore, Eka admitted that he was “strangled” with the assignments given to several courses at once. Lack of interactions between lecturers and students were seen during online lectures when the lecturers taught the material briefly so that “there is really no interaction with the lecturer... the lecturer only gives an explanation ... if it’s in Google Classroom, I can’t access it” (I1, Eka, 28-29, 32). Eka’s expression showed lack of support from the lecturer/teacher in the learning process. As a result, there was an imbalance between the time allocated for lecturer/teacher in the class and the tasks assigned to the students. He found out that more tasks were assigned during online learning. In addition, technology did not support him in his learning although the platform usage was effective for his sighted peers.

Eka tried to convince his peers to conduct the discussions in WhatsApp group by recording voices, but he got the rejection that made Eka finally use the Talkback application to help him read his friends' chat in WhatsApp group. However, Eka's concern might not be recognised by his peers as WhatsApp could meet the needs. During online learning, the absence of direct interaction between lecturers and students affects the subject's understanding of the material being taught. This finding supports the study conducted by Gupta et al on students in India that online learning lacks interaction between lecturers and students so that students' interest in learning decreases (Gupta et al., 2021). In addition, learning materials delivered in writing forms via WhatsApp are considered less of an opportunity for subjects with vision loss to actively engage in the learning process, thus having an impact on the learning outcomes of subjects with vision loss.

When Eka's problem was never addressed, his struggle to learn might be viewed as his personal issue. His struggle to participate in online classes was expressed as he confessed that he did not always understand the materials, which potentially increased his feeling of invisibility as his difficulties in learning may not be recognised and addressed, both by lecturers and peers. As a result, he could not participate actively and acquire rich and meaningful learning experiences, either by sharing his own experiences or receiving from others' experiences. Limitation use of learning platforms, as well as the availability of learning materials were subject to experience lack of accessible features that may influence engagement of students of vision loss. The use of learning platforms during the COVID-19 pandemic should facilitate the needs of all students, including those with vision loss.

The implication is that lecturers/teachers should make creative and reflective efforts in their digital competence when delivering their learning materials (Adedoyin & Soykan, 2020). Furthermore, lecturers/teachers should develop their pedagogical practices to create opportunities to provide rich, meaningful, and quality learning experiences for all students during online learning. Students with vision loss, such as Eka, should be supported to make the best use of online learning by attending to his struggles and needs. The presence of students with vision loss in the learning process should motivate lecturers/teachers to improve their competencies and skills, especially with regard to teaching diverse students.

b. Exercising more efforts

For Eka, who is a college student, the online learning policy implemented at the university has resulted in several impacts. According to Eka, his adaptation to online learning and lectures requires more effort, especially with regard to understanding the materials and the applications used to convey the lectures. In contrast to offline learning, Eka has taken a relatively longer time than his peers in completing assignments because Eka needs assurance from his sighted peers that the task has addressed the requirements.

> So I did the assignment then I sent it to my friends. "What do you think of my assignments?" or sort of things so that I understand the task … they have better understanding, right? So, they usually give me advice to revise the task …" (I2, Eka, 1,5-7)

Peers became a source for Eka to validate his understanding towards the learning materials. He believed that his peers were accountable, with whom he could check his progress in learning, whether he already met the task requirements. However, Eka mentioned that none of his peers ever asked him to clarify his understanding about what they learned. Finding of this study demonstrated that social support from peers was essential, not only for the individual student, but also for the class members in promoting collaborative learning. A literature study by Purwati et al. (in press) found that four articles suggested that support provided for students with disabilities by peers helped them cope with challenges of online learning, motivating these students to develop a positive mindset and feelings of responsibility. In so doing, students might be motivated to learn. However, the finding of this study showed that Eka tended to see his sighted peers as more knowledgeable than him. The implication of this finding was that lecturer/teacher should create opportunities for students to develop an atmosphere of collaboration and participation among students although the learning was held online. Students with and without vision loss were facilitated to learn from and contribute to one another's learning. This meant that students with vision loss should also be viewed as knowledgeable and eligible as a learner.

F. Conclusion

The purpose of this study was to present challenges experienced by people with vision loss during the COVID-19 pandemic in Indonesia. The study shows that subjects faced challenges in applying protocols, especially related to physical distancing. Issue of accessibility is addressed as a response to how the information about COVD-19 is distributed and how they make some adjustments to deal with those challenges. It is of utmost importance that challenges experienced by people with vision loss are addressed to increase their engagement and involvement in the mitigation preparedness plan for COVID-19. Attending the needs of people with disabilities, including those with vision loss during uncertain situations that should be addressed immediately is the main reason that they have to be included in a disaster plan management. Another implication of our findings can be found in addressing some potential invisible barriers that may present from the implementation of the health protocols of COVID-19 that could preserve the gap between people with and without disabilities in relation to the provision of health service.

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