Handling of Public Stigma on COVID-19 in Indonesian Society

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Abstract
Coronavirus disease 2019 (COVID-19) patients, their families, health workers, and cemetery officials are not only haunted by tragedies of the new coronavirus but are also stigmatized by the community. Stigma can be very detrimental to social life because it can be long-lasting without proper social measures. This qualitative study examined some cases of stigma in Indonesia. The interview was broadcast both live and online by a private television station, in April 15, 2020, and supplementary information was obtained from reliable news stories published by various mass media and from interviews with various groups of people. We identified the limited availability of personal protective equipment among health workers, a public lack of clear understanding regarding COVID-19, the distortion of news by various media, and a lack of clarity among those responsible for providing education, information, and communication. The government has not acted in a sufficiently prompt manner to prevent the spread of imported infectious diseases, resulting in local transmission and creating various stigmas among local communities. Although the infection has already begun to spread, the government must continue to ensure the correct understanding and clear mechanisms for how to prevent COVID-19 among the public.

Keywords: communication, COVID-19, education, information, public stigma

Introduction
Available information regarding the global coronavirus disease 2019 (COVID-19) pandemic was has been met with diverse responses among Indonesian society, resulting in the development of various public stigmas. Disinformation resulted in excessive caution, worries, and fear that were not balanced with empathy and sympathy for the victims.1 One nurse, who treated COVID-19 patients and had isolated herself from her family, was not welcomed into her neighborhood because her neighbors feared she would spread the virus, despite her application of the COVID-19 personal protective equipment (PPE) protocol. In another case, some nurses were evicted from their rented house because the owner feared that they would infect him.2 The first patient in Indonesia was discovered and announced by the President of the Republic of Indonesia, on March 2, 2020, which raised public concern and worries associated with the surge in virus transmission.3 By April 2020, one month after the first case of COVID-19 was detected, more than 8,000 COVID-19-positive cases were confirmed in Indonesia. Incorrect understanding, incomplete knowledge regarding COVID-19, and confusing guidance regarding socialization provided by public officials resulted in adverse reactions towards health workers, COVID-19 patients, and patients’ families.

The government attempted to reduce public turmoil with certain policies but did not provide sufficient information to increase public understanding. In some areas, stigma cases developed surrounding COVID-19 patients, patients’ families, and health workers. Almost five months have passed since the first case was detected, but the COVID-19 pandemic has not yet subsided. COVID-19 cases have been increasing since the disease was first discovered, in Wuhan, China, in December 2019, and was declared a pandemic by the World Health Organization (WHO) on March 11, 2020.4 By April 11, 2020, more than 1.69 million people, from 203 countries, had been infected, resulting in 102,000 deaths and 376,000 recovered patients.5

Over time, the concerns and stigma associated with the COVID-19 pandemic have become more terrible than the virus itself. As stated by the WHO’s Director-General, Tedros Adhanom Ghebreyesus, stigma is a...
The stigma associated with the coronavirus that emerged in local communities, threatening those who have tested positive for COVID-19 and the health workers who have been at the forefront, handling the outbreak. As a result, news stories reporting the refusal of medical personnel to treat COVID-19 patients in their homes, the public rejection of the dead bodies of health care workers, and individuals throwing stones at ambulances carrying COVID-19 patients are not uncommon. On one hand, these cases indicate public awareness and vigilance regarding the dangers associated with COVID-19, and the public is beginning to understand not to underestimate COVID-19. On the other hand, the fear of coronavirus and the efforts to maintain distance have been detrimental to humanity. Social distancing and physical distancing, should not result in the exclusion of people or the rejection of dead bodies. The coronavirus outbreak is predicted to continue for an extended period. Although some people would prefer to view themselves as safe and protected, we cannot predict whether this disease will eventually affect ourselves or the people we know. Therefore, negative labeling caused by excessive fear will only result in the loss of our sense of solidarity.

Many studies have demonstrated that stigma can worsen a disease, which has also been reported for the social stigma associated with COVID-19. Stigma is a major cause of discrimination and exclusion, affecting individuals’ self-esteem, disrupting family relationships, and limiting their abilities to socialize and obtain housing and jobs. Stigma can take the form of social rejection, gossip, physical violence, and denial of service. Naturally, we attempt to distance ourselves from people who can infect us. This disease avoidance reaction can result in people distance themselves physically from someone they believe to be suffering from an infectious disease. Stigma also arises from the belief that terrible circumstances befall people who make mistakes. This logical fallacy can cause people to believe that those who have become infected with a disease have done something wrong. People think that perhaps individuals who become infected with COVID-19 do not wash their hands properly, touch their faces too often, or do not maintain social distancing. These beliefs are especially common among individuals who believe they control their own destinies and that if one does everything properly, one will not get infected. However, we do not live in such a world. Although we can attempt to avoid COVID-19 by washing our hands for 60 seconds, instead of 20 seconds, the risk of infection remains the same.

Some individuals, such as ambulance drivers, must handle COVID-19 corpses daily, and these individuals are required to utilize PPE when delivering dozens of bodies to graves from several hospitals in Jakarta. These individuals work late into the night and are not allowed to return home fortwo tofive days due to the enactment of the Large Scale Social Restrictions that require a five-day isolation period for COVID-19-exposed individuals. However, COVID-19 cases continue to spread, indicating that means the community has not obeyed government regulations. The very empathetic driver may ask the public to stay at home so that he will not be required to continue delivering the bodies of COVID-19 patients. The burial regulations regarding COVID-19 patients in Indonesia mandates respect for the body, by avoiding the use of mass graves. The government protocol requires bodies to be buried, without the presence of family and visitors. Bodies can be buried in their family villages, but the remaining protocols must be followed.

Because of some of the described stigma cases, the researcher attempted to determine and analyze how public stigma associated with various groups affects health workers and other support staff who treat COVID-19 patients, the patients and their families, mass media exposure, and the understanding of COVID-19 in Indonesia.

Method

This study utilized a qualitative approach to some case studies in Indonesia, by gathering information from interviews that were broadcast live and online by one private television station, on April 15, 2020. These interviews were supplemented with information from reliable news sources and various mass media, including websites, such as kawalcovid19.id, galamedianews.com, jogja.tribunnews.com, nationalgeographic.grid.id, palu.tribunnews.com, jateng.tribunnews.com, and aceh.tribunnews.com; online media platforms, such as liputan6.com and kompas.com; and live discussions presented by ‘Mata Najwa’ on Trans7 TV.

This study was conducted during the COVID-19 pandemic, so the researcher could not perform face-to-face interviews. Primary information was obtained through interviews, moderated by virtually by a television channel.

The data were collected and analyzed, to explore problems associated with COVID-19 and to evaluate the perceptions and experiences of COVID-19 patients and caregivers, and the environment surrounding them until the patients have passed away.

The researcher framed the results of the interview to coincide with the concept of this study and performed a triangulation of the information provided during interviews with information obtained from reputable online media sources. The primary informants were professional and public figures, including the governor, mayor, the head of the Indonesian Medical Association, the head of the Indonesian Nursing Organization, sociology experts, psychologists, police, and village leaders.
Results

The information in this study was obtained from various informants with different backgrounds and characteristics, as shown in Table 1.

The informants' perceptions of the COVID-19 factors that cause stigma associated with excessive fear and worry, the factors that result in the emergence of stigma, and the efforts being made to eliminate stigma were evaluated.

a. Public perceptions of the health workers who serve COVID-19 patients and their families;

"Patients experience heavy days and must undergo treatment alone in the hospital. So, he was very sorry when there are people who push people suffering from COVID-19 away socially. There are even residents who refuse the COVID-19 corpse." (Informant-1)

"Because of the wrong perceptions and excessive fear from the community in her village in Ungaran, Central Java, which was also triggered by village leaders, caused the village members to reject the nurses' bodies in their hometown, the nurse who was a fighter on the front battle against COVID 19. The community refused because they were afraid of being infected by a body buried in the area. The village's head provoked the community to reject the body due to fear the virus might spread through the water under the ground. The community also refused the body because the deceased's residence was not initially in their village." (Informant-2)

"The residents fear the exposure to the coronavirus." (Informant-3)

b. Factors causing stigma against health workers who serve COVID-19 patients and their families;

"The influencing factors are the low level of knowledge about medical facts related to COVID-19, the low level of education, and the differences in perceptions between one person and another." (Informant-2)

"Education regarding the handling of COVID-19 corpse in the community is still lacking. Currently, health workers only use standards PPE in isolation and ICU rooms." (Informant-4)

"The residents fear the exposure to the coronavirus." (Informant-3)

c. Efforts to eliminate the stigma of health workers, COVID-19 patients, and their families;

"There should be more support from the people around the patient. Not only moral support, but also motivation, prayer, and positive energy are needed for the patient to go through various healing stages and meet their needs for at least 14 days so that patients can isolate themselves optimally. A patient who is positive without severe symptoms must inform the community to be alert and anticipated." Informant-1 suggested "living healthy with balanced nutrition, frequent hand-washing, wearing masks when outside of the house, and keeping a distance from others". (Informant-1)

"Efforts can be done with educating the public by role models, delivering positive charged news such as people who have recovered, the government should convey appropriate information and applying coping strategies (individual efforts to cope with pressure or problems) that are adaptive to the community." (Informant-2)

"There should be systematic handling of regional heads, religious leaders, TNI-Polri, and other parties in moving together." He continued "all health workers use PPE according to standards not only those in isolation and ICU." (Informant-4)

"[We] have coordinated with various parties so that nurses, doctors, and medical personnel who died from COVID-19 are buried in the Heroes' Cemetery in Central Java, anticipating a repeat rejection of the body including readiness for place and administration." (Informant-5)

"[To] increase the sense of humanity and togetherness, the officials, together with security forces, should ensure
that the government has handled it according to procedures so that it does not endanger the community, and the village administration allocates village funds to help the family’s basic needs because they undergo an independent quarantine.” (Informant-6)

“The community perceives that people who died from COVID-19 would still transmit the coronavirus; therefore, community leaders and local officials are needed to provide material and spiritual support to the deceased patient’s families or confirmed positive patient’s families.” (Informant-7)

“All COVID-19 corpse has followed the protocol of the burial screening that guarantee to not spread the virus because starting from the corpse wrapping until the burial, disinfectant is used several times and tightly closed.” (Informant-8)

According to Kompas media, on April 11, 2020, a nurse died from COVID-19 in a government hospital in Central Java while struggling to help her patients. The nurse’s body was intended to be buried in her village, in Ungaran, beside her father’s grave. Because of the wrong perceptions and excessive fear among the community in her village, in Ungaran, Central Java, which was also triggered by the village leaders, the village members rejected the nurse’s body. The community refused the corpse because they were afraid of being infected by a body buried in the area. The village’s head provoked the community to reject the body because of fear that the virus might spread through the water, underground. The community also refused the body because the deceased did not live in their village. The issues and opinions that arise without proper understanding can lead to excessive fear. Another nurse, from Dr. Kariadi General Hospital, Semarang who died while treating COVID-19 patients, was rejected from Sewakul Public Graves; thus, the body was eventually buried in a family funeral at Dr. Kariadi Hospital in Semarang. One informant, a psychologist at the Faculty of Education at the University of Persatuan Guru Republik Indonesia (PGRI) Semarang, stated that “the growing trend in the COVID-19 case has made the public worried, plenty of inaccurate information and reporting, community misunderstanding creates a negative stigma to Orang Dalam Pemantauan/ODP (Person Under Surveillance), Pasien Dalam Pemantauan/PDP (Patient Under Supervision), and COVID-19 positive patients and their families.” Learning that the nurse died from COVID-19 resulted in rejection from the public because of the stigma that the virus might spread if the corpse was buried in their hometown.

Furthermore, "stigma in the form of rejection, exclusion, ridicule, and harassment still exists, even though the socialization has been carried out by several regional heads, religious leaders, and Indonesian Medical Association.” Informing the public is not easy, even though when information is delivered by competent individuals.

Another interesting case was reported in Banyumas, Central Java. A positive attitude was identified in Banyumas, and the Regent participated in burying the body of a COVID-19 patient because of the previous refusal from the community. The governor intervened, apologizing to the families of the health worker, engaging indirect socialization, and asking epidemiologists and virus experts from well-known campuses, fatwas from religious leaders, village heads, and village officials to provide information and education to the public. The governor sent a proposal to the president of Indonesia suggesting that the country pay respects and show appreciation to health workers who have died while fighting against COVID-19 by burying them in the Heroes Cemetery. In addition, six professional health organizations in Indonesia released a joint statement, asking for the era of the stigma and discrimination displayed against health workers who fight COVID-19. The COVID-19 patients’ homes have also been stigmatized as presenting a transmission risk to surrounding communities. The governor’s effort to show appreciation to medical staff that have died while dedicating themselves to COVID-19 patients included the suggestion of presenting these individuals with a Hero Award by the President.

In Lampung, COVID-19 patients are rejected in one area but accepted in another area. The local community leaders in Lampung (‘RT’/neighborhood and ‘RW’/sub-village) would not help the first individual who died from COVID-19. Residents rejected the body, so his funeral was delayed for more than 24 hours. However, for the second case of death due to COVID-19 in Lampung, the residents worked together to prepare the funeral in the Sekicau Village, Sekicau District, West Lampung Regency, in April 4, 2020, and the body was buried in the Sri Galuh Environment Public Graves in April 5, 2020. Solidarity was essential in the face of the COVID-19 pandemic.

Discussion

Stigma in society can be bidevise, differing case by case; however, the sources of stigma tend to be similar, including a lack of information and the social environment. Stigma refers to the negative labeling of a person due to an environmental influence, which can be reduced or eliminated by implementing an effective strategy. The level of stigma associated with COVID-19 is based on three main factors: 1) the disease is new and many factors remain unknown; 2) we are often afraid of the unknown; and 3) the fear of the unknown can easily be associated.
with ‘others’. Understandably, confusion, anxiety, and fear regarding COVID-19 exist among the public. Unfortunately, these factors can also fuel harmful stereotypes. An effective strategy, such as strong interventions from the central/regional government, religious leaders, and security forces, is necessary to eliminate the negative stigma associated with COVID-19, reduce community anxiety, improve the status of victims, and optimize the resources of the community. Therefore, the patient’s families and the health workers who survive should not be isolated from the community because of stigma. Even if one does not want to help these individuals, patients, and their families should not experience additional stress associated with stigma, judgments, and even insults.

1. Stigma elimination

Stigma can damage mental health and worsens the condition of someone suffering from an illness. Being viewed wrongly by people can cause anxiety, stress, and even depression. Both stigmatized individuals and those who attempt to protect people from stigma can experience anxiety and stress.

Stigma affects people who are sick, people who have relationships with sufferers, and people who directly interact with the disease, daily. Family members and health care providers who treat patients with high-risk diseases experience stigma during pandemics. During the COVID-19 outbreak, stigma was also directed at people who have traveled from areas affected by the pandemic.

Stigmatizing anyone during a pandemic poses a threat to everyone. Study on HIV, Ebola, Hansen’s Disease, and other infectious disease epidemics have shown that stigma can be an obstacle to disease treatment. People who worry that they will be socially ostracized if they are sick tend to be reluctant to undergo testing for an illness or to seek treatment if they experience symptoms.

Not surprisingly, some patients being monitored (PDP) escaped from the hospital for fear of being positive for COVID-19. Logical fallacies may lead these individuals to believe that they cannot be infected with the disease because they have not made mistakes and have taken precautions to avoid disease.

Education is one of the most effective ways to stop the stigma. Regional leaders in centers with positive COVID-19 cases must be open regarding their diagnoses, to help normalize the disease. Similarly, celebrities and famous individuals who suffer from COVID-19 should also educate the public through social media. Posts on social media from celebrities who suffer from illness tend to help lift taboos. Their fans will be more intrigued if they discover that people they admire can also suffer from COVID-19. The trust that develops from this open sharing of information should not be broken, as the response to future outbreaks could be at stake. Another characteristic of this response is that the community has made use of social media to communicate and discuss ideas in real-time, enabling any interested member of the public to follow the data analysis and commentary provided by experts regarding outbreak control, genomic epidemiology, virus evolution, and coronavirus pathogenesis. Providing appropriate information, truth-telling, and transparent actions can augment the sense of civic responsibility and the willingness to volunteer among the public.

Information that reflects real conditions demonstrates the trust in society to judge situations fairly.

2. It is not social isolation

Social distancing is a term that is used to restrict public activities in an area. Social distancing aims to prevent the spread of coronaviruses, which can be transmitted through small droplets formed by coughing or sneezing. Maintaining physical distance does not mean that one should cut off social contacts with others; thus, the WHO has changed the phrase social distancing to physical distancing, to encourage global society to maintain social contacts with family and others while maintaining a physical distance. Although we should maintain distance from COVID-19 patients or those who are still being monitored, we can continue to communicate with them through other media, without being physically close. We can call or text our friends, relatives, or neighbors, especially those who are sick. We can also share the anxiety we experience with people we trust or with experts, through cyber space. Although stigma is a reaction designed to avoid illness, stigma is not sustainable. Stigma makes us scattered, but the COVID-19 pandemic reminds us that we are all connected. We are all susceptible to this virus, which should make us more united. We must remember that our enemy is COVID-19, not the sufferer. Prevent and fight the disease, not the person.

3. Clear education and information

The government should massively and comprehensively disseminate proper information, education, and communication regarding COVID-19. Informing the public regarding the identities of those who are affected and those who are handling COVID-19 is not necessary. The provision of education to the right target using appropriate cultural mechanisms for the local community can increase knowledge and eliminate negative stigma. For example, for People Living With HIV-AIDS (PLWHA), reducing negative stigma against them requires an increase in the available knowledge regarding HIV/AIDS.

4. Communication
Communication is the process of transmitting information and common understanding, from one person to another. Therefore, the recipient of the information can make strategic decisions by considering the conditions and situations (space and time) being faced into account, which can affect change in the public audience.

Establishing a communication strategy should consider several components. ‘Who delivers the message?’ not everyone is free to convey negative stigma. ‘What message should be conveyed?’ health workers and other supporting staff on the front line serve wholeheartedly, and victims who have died cannot transmit the COVID-19 virus because the host is not alive. The communicators should always ask the community to live according to Healthy Clean-Living Behavior. ‘What media does issue?’ by utilizing media and mass media networks and holding webinar forums, the direct delivery of information can be performed by experts or ordinary people. ‘Who is the communicant?’ this message should be targeted to all elements of society. ‘What effect is expected?’ the expected effect is that the community implements Healthy Clean-Living Behaviors, creates a positive stigma, and provides motivation and empathy for health workers, deceased victims, and their families.

5. Assistance from the government and security apparatus

Raising local champions in the community would support health workers. Creativity, led by community leaders and government officials, can increase empathy and improve understanding. Anxiety and fear can overcome empathy and sympathy when the public is presented with misinformation. Without empathy, the attitude that emerges in response to COVID-19 patients is likely to be avoidance and stigmatization of patients, their families, and health workers. The sympathy deficit results in negative stigma and can be discriminatory.

6. Best practice campaign

In Cimahi, a COVID-19-positive patient was assisted by his neighbors and his surrounding community through a majlis ta'lim (women’s association). They provided food to patients and their families, who were isolated in their homes. This support makes the patient and family feel content, which speeds the healing process. To supporting the patient to perform tests himself, the community supported him with an N95 mask, even though these were difficult to find at the time. The patient’s other family members had different religions and beliefs, indicating that tolerance is crucial for public health. The community’s participation, led by the head of the RT, demonstrated empathy, and providing correct information to the community can move the heart and soul of the community to generate humanitarians who will fight for the sake of public health.

Conclusion

In general, people in Indonesia did not clearly understand the COVID-19 epidemic, including transmission, management, and how to avoid it. This misunderstanding can extend the pandemic and the length of large-scale social restrictions. The central or regional government, together with local leaders/religious leaders and the local security apparatus, have the responsibility of delivering education, precise information, and accurate and appropriate communication strategies that align with the culture of the community, to increase community empathy and sympathy. The government and community must develop strategic, concrete, and decisive policies that are not confusing to the public and learn from the success of other countries’ experiences with the control of COVID-19 transmission.

Abbreviations

COVID-19: coronavirus Disease 2019; WHO: World Health Organization; PPE: Personal Protective Equipment; ODP: Orang Dalam Pemantauan (Person Under Surveillance); PDP: Pasien Dalam Pemantauan (Patient Under Supervision); ICU: Intensive Care Unit; TNI: Tentara Nasional Indonesia (Indonesian National Army); Polri: Kepolisian Negara Republik Indonesia (National Police of Republic of Indonesia); PGRI: Persatuan Guru Republik Indonesia (Teachers Association of the Republic of Indonesia)

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