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"They looked at me like I am a virus": how survivors cope with COVID-19 stigma during the early stage of pandemic

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ABSTRACT

COVID-19 has shocked everyone globally, with fears of contracting the disease and the other socio-economic impacts. The noticeable impact at the beginning of the COVID-19 pandemic was the emergence of mental health disorders in the community, especially for patients, namely the stigma labeled on them. This study aimed to explore the COVID-19 survivors' experience since they were declared positive and isolated, including the stigma they faced in the early stage of the pandemic, using a phenomenology approach. Eight informants selected through purposive sampling were contacted via in-depth online interviews during September-December 2020. All interviews were recorded, transcribed, and analyzed using thematic analysis. During the investigation, this research found two themes: encountering unpleasant impacts when contracting COVID-19 and coping strategies related to the impact. The negative stigma affected the informants' psychology and economics. Most informants took a religious/belief method to cope with the adversity, such as surrendering to God, and some reported ignoring the stigma. After one year of the pandemic, the stigma has dramatically reduced. However, continuous education in the community is needed to prevent stigmatization of COVID-19 survivors since the pandemic continues and scientific development in fighting this disease is ongoing. This research provides lessons learned to the community and related parties that mental health must also be a concern beyond the rapid response to disease control in a health emergency.

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1. INTRODUCTION

History records that the world has faced several severe pandemics. Nevertheless, it was still unprepared to deal with the current coronavirus disease 2019 (COVID-19) pandemic [1]. SARS-CoV-2 is the virus causing the COVID-19 illness discovered in China and then spread worldwide. It was subsequently declared a pandemic [2]. By April 2021, more than 130 million people worldwide had been infected with COVID-19, while more than 2,8 million people had died. At that time, Indonesia contributed approximately 1% to global cases and deaths [3]. The disease has a broad impact on health and the social structure of human life, such as adapting and changing behavior to prevent disease transmission. Another frightening impact of this pandemic is the social stigmatization of COVID-19 survivors and health workers treating COVID-19 patients [4], [5].

Stigma marks someone due to a social judgment that tends to a negative opinion and a desire to avoid or exclude those people being stigmatized. Stigma often occurs in health and is attached to individuals with an acute disease, for example, human immunodeficiency virus (HIV)-acquired immune deficiency syndrome (AIDS), mental health, and obesity. Today, the survivors of COVID-19, as well as health workers, have fallen victim to stigmatization. Some stigmatization incidents occur in different settings; for example, doctors and nurses could not use public transport [5]. While in India, during the COVID-19 crisis, stigmatization has occurred based on religion, occupation, race, and economic class [6]; in Indonesia, COVID-19 stigma is attached to survivors and health workers. For survivors, being stigmatized mainly affects their social relationships with others, such as feeling outcast due to being infected with COVID-19 [7]. At the same time, some healthcare workers have lost their rights to normal life [8]. The impact of stigmatization on a person can also be manifold, such as housing, income, education, social relationships, behavior, healthcare, and health [9]. Furthermore, stigma affects the individual, and associative stigma affects their family and/or those associated with them [10], [11]. However, studies exploring COVID-19 stigmatization at an individual level are still limited; most research has studied stigmatization in health workers.

According to Pryor and Reeder [12] there are four types of stigma: public stigma, self-stigma, structural stigma, and stigma by association. These are interrelated and can result in a negative outcome. How individuals cope with stigma can be divided into problem-focused and emotion-focused coping [12]. Stigma is considered dangerous for health systems because it is a fundamental inequality in health as it affects people's behavior towards health-seeking and public trust in the government. This means that it influences the public's response to the health program run by the government. There is mounting evidence regarding several diseases such as HIV-AIDS, obesity and mental health, stigma, and effects on individuals and society [13]–[15]. However, during the COVID-19 pandemic, information regarding stigma at the grassroots level remains limited, while the process of preventing and controlling COVID-19 must be carried out immediately. Therefore, studies on how the public stigma of COVID-19 affects the individual and how an individual with COVID-19 copes with the illness will enhance the understanding of the situation and, ultimately, how the health system should react.

During the early COVID-19 pandemic, Indonesia recorded relatively high morbidity and mortality. At the same time, the flow of information through the internet and social media cannot be controlled, which causes misinformation and disinformation related to this COVID-19. All of this triggers excessive fear from the public so that the stigmatization of COVID-19 fighters appears. This study aimed to explore COVID-19 survivors' experiences since they were declared positive and isolated, including the stigma they faced. We also captured how survivors cope with all adversities during the illness. This study contributes to providing lessons learned to the community and related parties that in a health emergency, mental health must also be a concern beyond the rapid response to disease control itself.

2. RESEARCH METHOD

2.1. Study design and participants

Our research employed a phenomenological approach to qualitatively analyze. It explored the experience of COVID-19 survivors facing social stigma, the impact on their lives, and how they coped with that situation. We emphasized personal experience and feelings to elaborate a pattern from which we can learn from their experiences.

Eight informants participated in this study and resided in two provinces: the Special Region of Yogyakarta and West Java. All of them were selected using purposive sampling. We approached informants personally through our social network because, at that time, the personal identity of a COVID-19 survivor was credentialed (not accessible to the public), and not all survivors we met were willing to be interviewed for fear of being stigmatized. The inclusion criteria for informants were: i) people who were diagnosed with COVID-19, ii) stating they were recovered when the interview was conducted, and iii) giving their consent to join our study. We determined to stop interviewing survivors who matched our inclusion criteria when our data were saturated.

2.2. Online interview

Interview guidelines were developed by the research group using relevant literature and in-depth discussion among the members. The interview guide consisted of some questions: i) Tell your story of being diagnosed to recover from COVID-19; ii) Tell your feelings after being diagnosed with COVID-19, and iii) Tell us how did you cope with that? iv) Who gave you support while in quarantine? v) Did you feel you were treated differently during your illness and afterward? vi) Did you suffer an economic loss because of your illness? Did your work suffer? How did you cope with that?

2.3. Data collection

Data collection was conducted from September to December 2020, meaning our informants had contracted COVID-19 before that period. We approached several COVID-19 survivors by stating the interests and objectives of this research. We then made an appointment for an online interview for the patients who agreed to participate. At that time, meeting in person was difficult due to human movement and social distancing. With the informants' permission, the interviews were recorded for analysis purposes. The interviews were conducted for an average of 45 to 60 minutes per informant. Oral informed consent was obtained from the informants at the beginning of the interview. The informants could withdraw from the research at any time if they wished.

2.4. Data analysis

Interview recordings were transcribed and analyzed using thematic analysis with a deductive approach [16]. Four people (authors number 1, 3, 5, and 6) independently looked for and obtained the transcriptions' meaning patterns to generate initial codes using the quirkos data analysis software. The first author then combined all the coding and searched for initial themes. In the next step, the themes were reviewed by all the authors through continuous discussion to agree on the theme name. Finally, we described and reported the analysis.

2.5. Ethical approval

The study was approved by the Ethical Review Board of Ahmad Dahlan University, Yogyakarta, Indonesia (ethical approval code: 012008029).

3. RESULTS AND DISCUSSION

We recruited two males and six females aged 23-65 with a mean age of 35.87±12.89. Five informants are married with children living in the same house, one informant is married with children who do not live in the same house, and two are single. Regarding occupation, three informants work in the government office (receive a monthly salary). One informant works at a private company (gets a monthly stipend), one informant was an entrepreneur in the traditional market (earns daily income), and three informants do not work. Concerning the isolation place: three informants were isolated at the government shelter, one informant was isolated in the hospital, one informant was isolated at home, one informant in a boarding house, and two informants underwent isolation at home, then in hospital as shown in Table 1. Two themes emerged from the analysis presented in Figure 1.

Table 1. Informant characteristics

ID	Sex	Education	Age	Occupation	Isolation place (duration)
A	Female	Diploma	42	Government office (Earns a monthly salary)	Government shelter (9 days)
B	Female	Diploma	27	Unemployed	Hospital (5 days)
C	Male	Senior high school	34	Government office (Earns a monthly salary)	Government shelter (8 days)
D	Female	Bachelor	28	Private company (Earns a monthly salary)	Home and hospital (16 days)
E	Male	Bachelor	42	Government office (Earns a monthly salary)	Home (3 days)
F	Female	Illiterate	65	Entrepreneur (Earns daily income)	Home and government shelter (23 days)
G	Female	Diploma	23	Unemployed	Government shelter (3 days)
H	Female	Ongoing bachelor education	26	Unemployed	Boarding house (22 days)

3.1. Theme 1: Encounter unpleasant impacts when diagnosed with COVID-19 and being isolated

This theme represents all feelings and events after the survivor had been diagnosed positive for COVID-19 and had to be isolated. All informants (n=8) dealt with various psychological experiences after testing positive for COVID-19 and having to be quarantined until they were declared negative/recovered. Informants experienced multiple forms of stigmatization from their surroundings. Being isolated and continuously stigmatized raised their negative emotions, such as feeling shocked after being diagnosed with COVID-19, feeling like it was a dream, and being surprised because they had applied health protocols so far (n=2). They were sad because they had to be away from family (n=3), feeling down and anxious about the possibility of death (n=2). Feeling insecure (n=2), this feeling arises after the quarantine had finished and they had to return to the community, fear (n=3), fear of transmission to the family and people around. They

were imprisoned (n=2), feeling like they were being punished alone, unable to go anywhere. Three informants stated they felt excluded by feeling people's attitudes, such as being rejected in their daily lives (n=4), and even at a further stage, experienced expulsion. Another form of stigma experienced is being shunned (n=7); this happened when people who had been close to them did not get in contact when the survivor was isolated–even via private chat. Three subthemes construct this theme:

i) Being stigmatized by society: excluded, rejected, and shunned

After being tested positive for COVID-19, the survivors experienced various unpleasant treatments, such as feeling neglected, rejected, and ostracized by the surrounding community, which hurt them. In times of isolation, many people stay away, even avoid communication and talk unpleasantly behind their backs.

> *"But we don't dare (to speak) because we're afraid people will say something else about me. That way, it's just that it's more painful than the disease itself."* (C, Male 34 yrs, isolated at government shelter)

> *"I'm still grateful (for not being kicked out of my house). My friend had to move from the boarding house because everyone looked at her like a virus. You can't even throw the trash out from the room."* (D, Female 28 yrs, isolated at government shelter)

Worse, when they are declared cured of COVID-19, they are still hostile, shunned, and refuse to carry out their everyday activities, such as shopping at the shop next to their house; the reason that people will be afraid of his presence.

> "*When I arrived home from the shelter, they asked whether I ran away from the hospital. It is such a rude question for me. When I went to the vegetable storehouse, the seller said that if I shopped in their storehouse, everyone would be afraid of getting infected by me. So, the seller not accept my presence on their storehouse*" (G, Female 23 yrs, isolated at government shelter)

In addition, other family members also experienced unpleasant treatment from the community, even though they had been declared curedl.

> *"My son* was *not allowed to play with the neighbors; they asked my son to go home. Then my son cried and went home."* (E, Male 42 yrs, isolated at home)

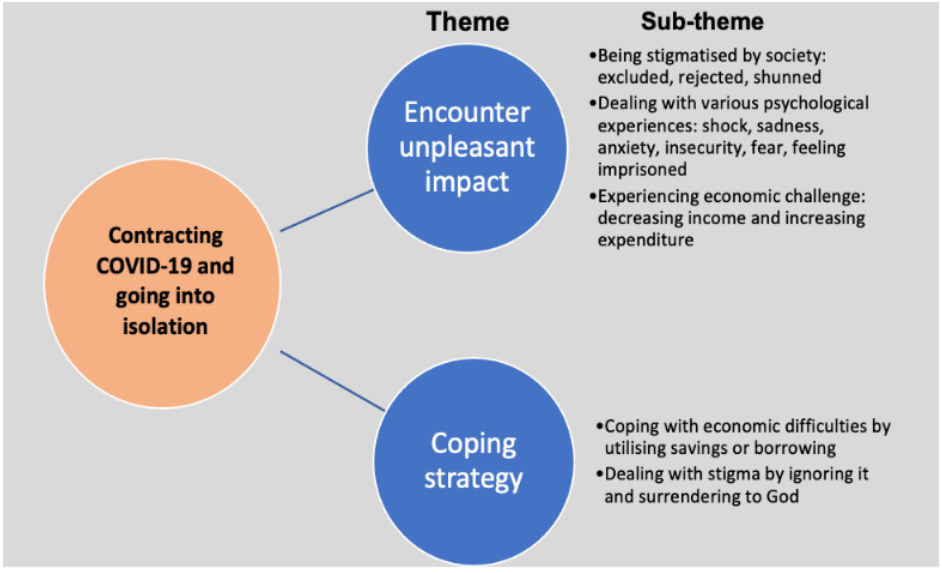

Figure 1. Summary of analysis using an inductive approach

ii) Dealing with various psychological experiences: shock, sadness, anxiety, insecurity, fear, and feeling imprisoned

Being infected with COVID-19 makes sufferers feel shocked, sad, and anxious. Moreover, they think they are imprisoned because they cannot carry out routine activities and must be isolated. One informant said he was in shock and stigmatized as the source of the virus.

> *"I was down at that time; they looked at me like a virus and dangerous thing. I am also worried because, logically (being hospitalized) means that we are in a virus house because it treats sick people. And now, there are people with corona, with different symptoms; some are severe."* (D, Female 28 yrs, Bachelor)

Another informant said he was unfortunate because he had to be separated from his family, even though he was worried about the COVID-19 situation.

> *"*Sad *because you must leave your family, be isolated, and continue to be anxious. The anxiety is whether COVID-19 can be cured or not. There are only two possibilities for COVID-19: alive or dead because the mortality rate shows so."* (A, Female 42 yrs, Diploma)

iii). Experiencing economic challenges: income decreasing and expenditure increasing

During isolation, COVID-19 sufferers cannot have economic activities, so they cannot get their primary income, mainly for informants who did not receive regular monthly salaries. On the other hand, during the isolation, the need increased because there were purchases of multivitamins and other supporting foods as well as routine needs that must be met.

> *"There is a decrease of about 60% in income because my husband is self-employed. On the other hand, there is an increase in expenditure of about 30% from normal, not because of drugs but for food nutritional intake to speed up the recovery."* (D, Female 28 yrs, works at government office)

Informants working in the formal sector that receive regular income also reported a slight decrease in income.

> *"My husband works in a private hospital, so it seems that his income is affected because he didn't go to work for several days. But yes, only a little."* (A, Female 42 yrs, works at government office)

3.2. Theme 2: Coping strategies to overcome the unpleasant situation

The second theme is the coping strategies used to overcome the worst situation, representing how they coped with their problems during quarantine (isolation). An interesting finding was how informants handled the situation they faced during the illness and isolation. Two out of the eight informants said they overcame decreased income and increased expenditure by using savings for economic issues. One other informant stated that they borrowed money from others. Meanwhile, five of the eight informants expressed that they were helped by their support system-for example, logistical assistance from their employer. On the other hand, four informants said they chose to surrender what happened to God. To overcome the stigma, informants ignored it (n=2). Two subthemes were developed for this theme:

i) Coping with economic difficulties by taking out savings or a loan

As mentioned before, during the isolation, COVID-19 survivors experienced a decrease in income and an increase in expenses, so they had to find a way out to deal with it. For those who have savings, they will withdraw their money.

> *"I have unpredicted money; usually, I keep it somewhere in my room. So yesterday, I took it during my recovery."* (G, Female 23 yrs, unemployed)

However, for those who do not have reserve funds, they must borrow to meet their needs:

> *"I meet daily needs by borrowing from anyone. I buy food from a peddler but pay later. I have the principle as long as I'm still alive, I can still pay my debt."* (F, Female 65 yrs, entrepreneur)

ii) Dealing with stigma by ignoring it and surrendering to God

The stigmatization of people with COVID-19-even when they are declared cured-leaves survivors with no choice nonetheless to face it.

> *"It's sad (what they do to me), but I just ignore it; maybe they don't know about COVID-19. The important thing is I don't interact closely with them. I surrendered (with COVID-19), but I thought this was already the way, and there must be a lesson. With the name of God, "Kun Faya Kun," if God wants it, it will happen, and we have only to pray."* (A, Female 42 yrs, Diploma)

iii) Surrendering and considering this a life trial from God was also stated by another informant

> *"I surrender and believe in God, pray and pray. I have given up because I don't know what else to do; maybe this is a life test for my family."* (B, Female 27 yrs, Diploma)

This is one of the first studies to explore the stigma associated with COVID-19 survivors and their coping strategies in Indonesia. We found that the survivors dealt with several social stigmatizations that affected their psychology and economics in the sample. The survivors' coping strategies during the period of isolation included turning to religion through surrendering to God and ignoring people's opinions. The survivors borrowed money from others and drew on their savings to cope with the economic adversity.

We reveal the psychological experiences of the COVID-19 survivors who were infected at the onset of the disease (2020) in Indonesia. In-depth interviews with the recovered survivors reported many horrible psychological experiences during their illness and isolation, including being excluded, rejected, and ignored by their community/neighbors. Thus, in line with the WHO statement, stigma is more hazardous than the disease itself [17]. The stigmatization of certain conditions is not new in public health. Mental health has always received a negative stigma from the community, dissuading sufferers from seeking treatment [18]–[21]. If the social stigma labels of COVID-19 patients continue, it will hinder general prevention efforts of this disease; COVID-19 patients refuse to seek treatment and mask the disease symptoms for fear of being stigmatized by the surrounding community [22], [23].

Our informant stated that COVID-19 stigma and harassment influence societal psychological and mental behavior, following the previous research [17]. The experiences of the COVID-19 survivors and the news in the media about the COVID-19 stigma scare the public. Indonesia's situation has worsened: people with symptoms do not want to be tested for fear of being stigmatized [24], while local communities refuse COVID-19 corpses because of excessive fear [25]. Consequently, when people are diagnosed with COVID-19, they feel shocked, sad, anxious, and insecure; they are terrified by the stigma. These feelings reflect their panic and unreadiness to accept the reality-being infected with COVID-19, being isolated, and being stigmatized by society. What has happened in Indonesia is not unique; the same panic has been witnessed in the Philippines in response to COVID-19. The panic phenomenon in the community during the COVID-19 pandemic is a form of anxiety due to misperceptions and difficulty finding solutions [26]. This is understandable because, at the onset of the disease, there was a lack of information about COVID-19. Meanwhile, there was a rapid flow of information through social media, including false information/hoaxes that generated panic among people [27], [28]. In Indonesia, as we found in our previous research, there is insufficient knowledge in society about such issues as air transmission and COVID-19 symptoms [29], which affect the general attitude towards and the prevention of the disease, including how COVID-19 survivors should be treated.

Most COVID-19 survivors coped with social stigmatization using emotion-focused coping [12] by denying or ignoring what people said. The survivors also accepted their situation as God's predestination (Allah); they adopted an attitude of surrender. This situation captures the role of religion/spiritual belief in determining a person's attitude. Previous research states that more religious people have better mental health when facing illness or health problems than less religious people [30]. This evidence opens another possibility for education-as the primary pathway to reducing stigma-through religious leaders cooperating with the relevant health authorities. The spiritual leader model has been implemented in health problems, such as the diabetes campaign in Mexico and increased vaccination acceptance amongst minority groups in the Netherlands [31], [32]. In Indonesia, the government, through the Indonesian COVID-19 task force, has developed some measures to tackle the COVID-19 stigma: i) presenting better communication regarding the risks, ii) encouraging the media to spread complete and correct information about the transmission of the virus to avoid misinformation and misinterpretation that could affect society's behavior regarding COVID-19 prevention and control, and iii) fostering the media to present balanced information, not only about the number of cases but also regarding the prevention and control efforts in an attempt by the government to avert people's fears [33], [34].

The isolation and stigmatization of the COVID-19 survivors had a direct economic impact mainly on people who do not have a regular salary, for example, unemployed or entrepreneurs. People without a stable income/financial independence are more vulnerable and less resilient during this pandemic. Fortunately, Indonesian society possesses good social capital in cooperation or mutual assistance, called *Gotong Royong* [35], [36] that provides social support to the COVID-19 survivor during their illness, as mentioned by the informant. This is evident in the social actions/solidarity in several places in Indonesia to support isolated COVID-19 survivors, especially those isolated at home who cannot meet their daily needs. For example, in Yogyakarta Province, some social solidarity acts were raised aimed at providing the COVID-19 survivor's logistics during isolation, called *'Solidaritas Pangan Jogja (SPJ),' 'Jaringan Lintas Iman Tanggap COVID-19 (JIC)', and Gandeng Gendong* [37]–[39]. This kind of social action is also found in other areas in Indonesia, with concern for the surrounding community. This model can be further developed as a construct to alleviate the current social crisis in the community. However, what has happened regarding the social exclusion of COVID-19 survivors signals that the social capital structure, namely togetherness, is weakening in Indonesia.

Possible weaknesses of the study are the number and the distribution of informants' locations because, in the early pandemic, the identity of the COVID-19 case was closed to the public, and some prospective informants refused to be interviewed for fear of violating restrictions. Nonetheless, saturation was reached with the informants we engaged, i.e., there was no more new information from the informants. We recommend using a mixed-method approach, with the general public as the subject, to assess their response to COVID-19 survivors for future research. Another potential study is examining the role of social capital in society during a health emergency. For the health authority, education is the primary method of informing the community regarding COVID-19. Engaging prospective change agents such as spiritual leaders may enhance the belief in, and acceptance of the information delivered.

4. CONCLUSION

This study explores COVID-19 survivors' experiences during their illness and being isolated, including the stigma they faced. We interviewed eight COVID-19 survivors after being declared hostile to COVID-19. Findings show all the COVID-19 survivors in this study experienced COVID-19 stigma from their neighbors during and even after their illness. Having a good support system and religion/belief is crucial to facing stigmatization. After one year of the pandemic, the COVID-19 stigma in Indonesia is already much reduced. However, continuing education in the community is still relevant and essential to avoid the same stigma while the scientific effort to defeat COVID-19 is ongoing.

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