



# Psychological Changes and Stigma Experienced by Family with Covid-19

Arnika Dwi Asti<sup>1\*</sup>, Putra Agina Widyaswara Suwaryo<sup>1</sup>, Siti Mastuti<sup>1</sup>

<sup>1</sup>Nursing Department, Universitas Muhammadiyah Gombong, 54412, Indonesia  
Corresponding author's email: [arnikadwiasti@gmail.com](mailto:arnikadwiasti@gmail.com)

## ABSTRACT

The Indonesian government declared COVID-19 a national disaster on March 14, 2020. On October 31, 2020, there were 1,342 confirmed COVID -19 cases in Kebumen Regency: 3 people were confirmed to be referred, 162 people were isolated, 40 people were confirmed dead, and 1,062 people recovered. People are afraid of the COVID-19 virus because it is highly contagious, so they avoid interacting with patients and their families. As a result, the family has experienced psychological changes and feels stigmatized. The purpose of this study was to describe the psychological changes and stigma experienced by caregivers who treat 19 patients. This is a qualitative study using a phenomenological descriptive method. Snow ball sampling was used to select participants for this study until data saturation was reached. They are a member of the family and care for the covid 19 patients. This study included a total of ten clients. Stevick-Collaizi and Keen's structured approach to data analysis was used. The research revealed three major themes: (1) Psychological changes, which include three subthemes: psychological disorders, the adaptation process, and the stigma received; (2) Conditions during illness and treatment, which include three subthemes: early treatment, activities during illness, and the meaning of illness; and (3) the accepted support system, which includes two subthemes: from family and friends and from the community. Significant psychological changes are taking place, the adaptation process is underway, and some people are stigmatized. Health care providers must be able to assess the psychological conditions and adaptation processes of the covid 19 patients in order for the nursing care process to be holistic, including bio-psycho-social and spiritual aspects.

**Keywords:** *Care Giver of Covid-19 Patients; Psychological Changes; Stigma*

## 1. INTRODUCTION

The coronavirus disease (COVID-19) was first reported infect humans in December 2019 in Wuhan, China. WHO reported that on March 13, 2020, COVID-19 cases were found in 122 countries, with a total of 132,758 confirmed cases and 4,955 deaths (CFR=3.73%) and then the status was upgraded to a global pandemic [5][6].

In Indonesia, according to data from the Ministry of Health (2020), COVID-19 has been declared a national disaster since March 14, 2020. As per October 31, 2020, the number of confirmed cases was 410,000, the number of patients recovered was 337,801 and the number of victims died was 13,869. A total of 67,008 people are still under monitoring, 13,439 patients are under surveillance and 58,418 people are still under treatment, besides that 67,900 other people have been declared suspicious. On October 2020, COVID-19 cases were recorded in all

provinces in Indonesia. In detail, it was stated that there were 502 regencies/cities from 34 provinces that were affected by the corona virus transmission. This shows that more than 97% of areas in Indonesia have been affected by the Covid-19 pandemic.

Central Java Province is ranked fourth in Indonesia for the prevalence of Covid-19 (Central Java Health Office, 2020). Meanwhile, the number of confirmed Covid-19 cases in Kebumen Regency as of October 31, 2020 was 1,342 people, 3 people were confirmed to be referred, 162 people were isolated, 40 people were confirmed dead, and 1,062 people recovered. According to the most recent Covid-19 distribution in Kebumen Regency, there are 27 suspected cases and 99 probable cases, of which 50 were treated and 49 died (KEBUMEN Health Office).

Based on updated data from the Kebumen Regency website on October 20, 2020, the map of the distribution of COVID-19 sufferers is evenly distributed in all sub-

districts in Kebumen Regency with 986 confirmed positive numbers of COVID-19. Those who experience symptoms are referred for health care services at COVID-19 referral hospitals such as PKU Muhammadiyah Gombong Hospital, RSUD dr. Soedirman Kebumen and Prembun Hospital. Meanwhile, those who are confirmed positive for COVID-19 without symptoms are self-isolating at home for 14 days.

The rapid development of the Covid-19 pandemic has affected and had a major impact on people all over the world socially, mentally, physically, psychologically and economically. Being infected with Covid-19 is considered a serious health problem and causes severe psychological trauma to both healthy groups of people, sick people, and health workers who treat them. Individuals also experience feelings of stress, worry, and anxiety about the uncertainty of the end of the condition.

The characteristics of the COVID-19 virus, which is very easily transmitted and there is no cure, makes people feel afraid of those who are confirmed positive for COVID. This causes people to view negatively and avoid interaction with patients and their families, even when the family has not been confirmed to be positive for COVID. This is a form of stigma, namely prejudice those discredits or rejects a person or group because it is considered different from most people given by society and is influenced by the environment. The causes of the emergence of stigma consist of religious and cultural beliefs, level of knowledge, misinformation received by individuals by the environment, and lack of experience related to existing problems.

Based on the results of interviews with 3 care givers, patients who were confirmed positive for COVID-19 stated that they experienced psychological changes and received stigma from the environment. They expressed anxiety about their condition because they had to take care of themselves so they wouldn't get infected and take full protection during the treatment process. They stated that relatives and some neighbours helped meet their needs while self-isolating. But some of the others looked frightened, avoided and talked behind their backs.

## 2. METHOD

This study uses a qualitative method with a descriptive phenomenological approach. The research sample of 10 COVID-19 family was taken using the snow ball sampling technique with inclusion criteria: a member of COVID-19 patients and do a role as caregiver, do self-isolated at home, adult (>18 years), and willing to participate. Participants were then conducted in-depth interviews until data saturation emerged. The validity of the interview data was tested using 4 principles: credibility, dependability, confirmability, and transferability. Data analysis of the research results used the Stevick-Collaizi and Keen method through the stages

of making transcripts of interview results, finding keywords, arranging keywords into categories and themes, then making a complete description of research results [3].

## 3. RESULT AND DISCUSSION

### 3.1. Result

The research discovered three main themes: (1) changes in psychological conditions (psychological disorders, the process of adaptation experienced, and stigma received), (2) conditions during illness and treatment, which includes three sub-themes: early diagnosis, activities during illness, and the meaning of illness, and (3) the received support system, which includes two sub-themes: from family and friends and from the community and village.

#### a. Theme 1. Changes in Psychological Conditions

Changes in psychological conditions consist of 3 sub-themes, namely psychological disorders, the adaptation process experienced and the stigma received.

Sub-theme 1.1 Psychological disorders: experience fear (4 people), sadness (6 people), and anxiety (4 people). They say:

"I'm afraid if it's going worse ..." (P4)

"I thought about various things. How we have to earn money, we are isolated ..." (P2)

"I am afraid that he will die..." (P3)

"I thought about various things because at that time she had a fever and complained of body aches..." (P1)

"Worried about what kind of severe symptoms will be, so he was immediately taken to the hospital..." (P10)

Sub theme 1.2 Experiencing an adaptation process in the form of rejection (5 people), bargaining (2 people) and acceptance (10 people). They say:

"Astaghfirulloh...how come the father is positive..." (P2)

"I had a feeling why I got sick even though it was very strict to maintain health protocols..." (P5)

"I put my trust in Allah, surrender, that's all..." (P9)

Sub-theme 1.3 Experiencing stigma where some stated that they received stigma as being considered dangerous and shunned (4 people). Some stated that they did not accept the stigma (6 people). They say:

"The neighbours are astonished; how come they eat it with a gojek. Never leave the house..." (P1).

"I got angry with my friends. It was said that at first the office colleagues were positive because me..." (P3).

"Thank God it's good, there's no fear, there's nothing..." (P2)

"Neighbours can accept..." (P7)

## b. Theme 2. Conditions During Sickness and Treatment

In this theme, there are 3 sub-themes: initial action after diagnosis, activities during illness and the meaning of illness.

Sub theme 2.1: Initial action after diagnosis consists of evacuating family members (2 people) and isolating themselves (10 people). They say:

"I immediately evacuated my child to the maid house, my parents told me to go back to their own house ..." (P1)

"As soon as I found out it was positive, I didn't leave the room anymore and immediately took the swab test"(P4)

"Separate room for our family" (P3)

Sub theme 2.2: Activities carried out during illness consist of worship activities (10 people), sunbathing in the morning (8 people), watching TV (8 people), taking care of eating, drinking and sleeping (10 people). They say:

"I play online games on my cell phone so I don't get bored..." (P4).

"Sunbathing in the morning, exercise for a while then continue to pray *dhuha* ..." (P5).

"Sleep, eat, drink... Yes, it's like that." (P9)

Sub-theme 2.3: The meaning of pain experienced is felt as a test (3 people) and closer to Allah (7 people). They say:

"This is a test from Allah..." (P2)

"So closer to Allah, pray more all the time..." (P7)

## c. Theme 3. Support Received During Sick

This theme consists of 2 sub-themes: support from family and friends, support from the community.

Sub-theme 3.1: support from family and friends was expressed by participants by stating that they were given support by their family (10 people), support from friends in the WA group (10 people) and assistance with basic necessities and vitamins from the office (6 people). They say:

"Brothers and sisters provide support through the family WhatsApp's group" (P3).

"Friends joke and video calls via WhatsApp's" (P1).

"From the office, you can get a lot of basic necessities and vitamins" (P6).

Sub theme 3.2: Support from the community is received from neighbours in the form of food and vegetables (7 people). Support from the village government was obtained in the form of food packages (6 people). They reveal:

"Because we in the village every day there are neighbours who give food, give vegetables ... that's the turn every day ..." (P2).

"Many neighbours pray for, give support..." (P5).

"The people here are kind, madam, accept me as the situation is like this, in fact they often help me and my family when I'm in trouble" (P6).

## 3.2. Discussion

Theme 1: Psychological changes experienced in the form of psychological disorders of anxiety, sadness and fear. Some participants felt stigmatized even though others did not feel it.

According to the literature, the level of anxiety symptoms in COVID-19 patients and their families was relatively high (6.33 percent to 50.9 percent), depression (14.6 percent to 48.3 percent), mental disorders post-traumatic stress (7 percent to 53.8 percent), psychological distress (34.43 percent to 38 percent), and stress (8.1 percent to 81.9 percent) were reported in the ge. This is consistent with research indicating that the outbreak is causing additional health issues worldwide, such as stress, anxiety, depressive symptoms, insomnia, denial, anger, and fear. Collective concerns influence policymakers' daily behaviour, economics, prevention strategies, and decision-making, potentially undermining COVID-19 control strategies and leading to increased global morbidity and mental health needs. [11].

The stigma experienced by some COVID-19 patients and their families is consistent with previous research on the stigma experienced by COVID-19 survivors versus healthy controls following the peak of the COVID-19 outbreak in China. The sample included 154 COVID-19 survivors and 194 healthy control groups recruited using the consecutive sampling method. The Social Impact Scale assesses stigma associated with COVID-19 (SIS). In this study, the differences in stigma between the two groups were compared using analysis of covariance (ANCOVA) and the generalized linear model (GLM), which were used to identify the independent correlation of COVID-19-associated stigma. COVID-19 survivors reported more stigma overall ( $F(1.347) = 60.82, p 0.001$ ), stigma in the social rejection domain ( $F(1.347) = 56.54, p 0.001$ ), financial insecurity ( $F(1.347) = 19.96, p 0.001$ ), internalized shame ( $F(1.347) = 71.40, p 0.001$ ), and social isolation ( $F(1.347) = 34.73, p 0.001$ ). The factors that cause community stigma against COVID-19 are the level of knowledge that affects individual perceptions and actions and the dissemination of information that is not credible. The form of stigma given can be in the form of discrimination, labelling and stereotyping. The impact of stigma COVID-19 can create obstacles to contact tracing so that it has an impact on case reporting and stress and has the potential to interfere with mental health [12].

Theme 2: Conditions During Sickness and Treatment. In this theme, there are 3 sub-themes, namely initial action after diagnosis, activities during illness and the meaning of illness. When the patient is diagnosed with

COVID-19, he immediately takes action to evacuate family members and carry out social isolation at home. They immediately decide the path of interaction with family and social environment. This is intended as social distancing to prevent transmission of the virus to others. An American study assessed the effectiveness of six government-imposed social distancing policies, including state-wide stay-at-home orders, limited stay-at-home orders, non-essential business closures, bans on large gatherings, school closures, and restrictions on weekday visitors to restaurants and bars. pandemic. According to the findings, stay-at-home orders had the greatest impact on reducing mobility outside the home and increasing the amount of time people spent at home by about 2.5 percentage points (15.2 percent). Restriction on restaurant and bar visits came in second, with a 1.4 percentage point increase in home attendance (8.5 percent). This influences the massive spread of the COVID-19 virus [1]. According to Chinese research, as of April 13, 2020, there were 309 cities with zero cases and only 34 cities with confirmed cases following a series of social distancing measures. This demonstrates that social distancing is the most effective measure for halting the transmission of covid 19 [13].

During social isolation, most of the activities carried out are sunbathing, resting, watching television and maintaining a healthy eating and drinking pattern. The recommended activity during social isolation is regular exercise. Exercise offers many benefits such as boosting the immune system, improving bone health and lowering health risks such as heart problems, diabetes and many more life-threatening diseases. WHO and a number of other stakeholders emphasize the role of physical activity during the COVID-19 response [4].

Families of COVID-19 patients feel the pain as a test. They accept it and draw them closer to God. During their illness they feel an increase in the spiritual side. Previous research has suggested that spirituality and religious practice are protective factors that are not only associated with psychological and mental health, but also physical health [2].

Theme 3: Help Received During Illness. This theme is divided into two sub-themes: family and friend support and community support. Previous research on employee family support during a pandemic has found that employee family support has a positive longitudinal effect on work outcomes during a pandemic [9]. In terms of community social support, a study in Central Java found that social support plays an important role in morally and materially strengthening families who have tested positive for Covid-19 in their daily lives. Furthermore, emotional support (asking for news, encouraging), instrumental support (fulfilling basic needs, household needs, and medicines), informational support (disinfection and closing of road portals), and indifferent support are all forms of social support

obtained from neighbours. While forms of social support obtained from colleagues include encouraging and not isolating, assisting administrative needs, and providing logistical and financial assistance [8].

#### 4. CONCLUSION

There are psychological changes and the stigma received by the families of covid 19 survivors. They also experience a process of adaptation that is not easy. Health care providers must be able to assess changes in psychological conditions experienced, stigma that may be felt and the adaptation process experienced by individuals so that the nursing care process can take place holistically including bio-psycho-social spiritual aspects.

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#### REFERENCES

- [1] Abouk, R., & Heydari, B. (2021). The Immediate Effect of COVID-19 Policies on Social-Distancing Behavior in the United States. *Public Health Reports*.  
<https://doi.org/10.1177/0033354920976575>
- [2] Coppola, I., Rania, N., Parisi, R., & Lagomarsino, F. (2021). Spiritual Well-Being and Mental Health During the COVID-19 Pandemic in Italy. *Frontiers in Psychiatry*.  
<https://doi.org/10.3389/fpsy.2021.626944>
- [3] Cresswell, J. W. (2017). Research Design Pendekatan Kualitatif, Kuantitatif, dan Mixed Edisi ketiga. In *Yogyakarta: Pustaka Pelajar*.
- [4] Elmagd, M. A. (2020). Sports and physical activity during ( COVID-19 ) pandemic. *International Journal of Physical Education, Sports and Health*.
- [5] Nurkholis. (2020). Dampak Pandemi Novel-Corona Virus Disiase ( Covid-19 ) Terhadap. *Jurnal PGSD*.
- [6] Özdemir, Ö. (2020). Coronavirus Disease 2019 (COVID-19): Diagnosis and Management (narrative review). *Erciyes Medical Journal*.  
<https://doi.org/10.14744/etd.2020.99836>
- [7] Qian, M., & Jiang, J. (2020). COVID-19 and social distancing. In *Journal of Public Health (Germany)*.  
<https://doi.org/10.1007/s10389-020-01321-z>
- [8] Rahmatina, Z., Nugrahaningrum, G. A., Wijayaningsih, A., & Yuwono, S. (2021). Social support for families tested positive for Covid-19: dukungan sosial pada keluarga yang divonis positif Covid-19. *Proceeding of Inter-Islamic University Conference on Psychology Articles*.



- [9] Shin, Y., Hur, W. M., & Park, K. (2021). The power of family support: The long-term effect of pre-COVID-19 family support on mid-COVID-19 work outcomes. *International Journal of Environmental Research and Public Health*. <https://doi.org/10.3390/ijerph181910524>
- [10] Sukmana, M. (2020). The pathogenesis covid-19 in the context of establishing a nursing diagnosis. *Jurnal Kesehatan Pasak Bumi Kalimantan*.
- [11] Torales, J., O'Higgins, M., Castaldelli-Maia, J. M., & Ventriglio, A. (2020). The outbreak of COVID-19 coronavirus and its impact on global mental health. In *International Journal of Social Psychiatry*. <https://doi.org/10.1177/0020764020915212>
- [12] Wanodya, K. S., & Usada, N. K. (2020). Literature Review : Stigma Masyarakat Terhadap Covid – 19. *Preventia: Indonesian Journal of Public Health*.
- [13] Xiong, J., Lipsitz, O., Nasri, F., Lui, L. M. W., Gill, H., Phan, L., Chen-Li, D., Iacobucci, M., Ho, R., Majeed, A., & McIntyre, R. S. (2020). Impact of COVID-19 pandemic on mental health in the general population: A systematic review. In *Journal of Affective Disorders*. <https://doi.org/10.1016/j.jad.2020.08.001>

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