

The feeling of fear of families with stroke survivors to the threat of COVID-19

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Abstract

Purpose: The purpose of this study was to explore the fear feeling of family and the threat of COVID-19 in stroke survivors. **Methods:** This study uses a qualitative method with a phenomenological research design. This study is a nested research in the population of HDSS Sleman, so it uses secondary data from stroke survivors' information. The research informants amounted to 8 people. Data collection was carried out in July-August 2021 in Kecamatan Depok Kabupaten Sleman. In-depth interviews and photo documentation were carried out in data collection. Data were analyzed using OpenCode version 4.2. **Results:** The health status of the stroke survivors at the time of the interview had recovered before the pandemic, died during the pandemic but was not caused by COVID-19, and were still in a state of stroke. All informants or families of stroke survivors showed the same fear response to the threat of COVID-19. Families who care for stroke survivors think that those who are at risk and vulnerable to being exposed to COVID-19 are older people and those who have comorbidities. Fear arises because it is influenced by the perception of oneself and the surrounding environment. There are fears in the form of the assumption that they might be exposed when carrying out examinations and treatment at health facilities, fear of doing swabs, and the financing of COVID-19 testing and the number of positive cases. **Conclusion:** The fear of the vulnerability of stroke survivors when exposed to the COVID-19 virus is shown by families of stroke survivors by avoiding visits to health facilities, be it puskesmas or hospitals, and choosing to anticipate themselves at home. The fear of the families of stroke survivors must be a concern for the healthcare institutions that protect them so that treatment and health services for stroke survivors with comorbidities during the pandemic can still be achieved.

Keywords: comorbidities; family of stroke survivors; stroke; the fear of the threat of COVID-19

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INTRODUCTION

Coronavirus Disease 2019 (COVID-19) has become a global pandemic since WHO determined it on March 11, 2020. COVID-19 is an infectious disease caused by Severe Acute Respiratory Syndrome Coronavirus 2 (SARS-CoV-2). According to data from the Ministry of Health on January 23, 2021, Indonesia recorded approximately 977,474 positive cases, 83,190 suspects were monitored, and 27,664 deaths were reported. Jakarta was the first area identified; other provinces reported the same cases. The Province of the Special Region of Yogyakarta is also an area that is also affected by the COVID-19 infection. Data dated January 23, 2021, shows 19,209 positive cases and 430 deaths due to COVID-19 [1]. Statistical data from the local government of the Special Region of Yogyakarta showcases and deaths in the Sleman district.

COVID-19 is a real threat to physical and emotional health. People fear that they or those close to them will fall ill or die, which can have psychological effects [2]. COVID-19 is also a threat to people who have a history of specific comorbidities. A systematic review study and meta-analysis showed that cerebrovascular disease (stroke) is one of the chronic comorbidities that is a risk factor for aggravating or death associated with COVID-19 [3]. Published studies show cerebrovascular disease is associated with a 2.5 times increased likelihood of disease severity in patients infected with COVID-19 [4].

The incidence of stroke in Indonesia has increased sharply; even now, Indonesia is the country with the most significant number of stroke survivors in Asia. Stroke prevalence based on diagnosis in DIY was 14.6% and increased from 2013 [5]. Data on Health Demographic Surveillance System Sleman (HDSS) Indonesia, in 2016, using the data collection method in the form of self-reported diagnosis, found 198 stroke survivors, and in 2017, using data collection in the form of self-reported symptoms, found 55 people with stroke. The most stroke survivors in Depok District were 36 people in 2016 and 11 people in 2017.

Research on stroke care shows that during a pandemic, health workers (doctors and nurses) must monitor and protect stroke survivors from Coronavirus infection and also because of complications of disease severity associated with COVID-19 [6]. Therefore, it is also essential to look at the views of families about stroke survivors living at home.

Other studies have also shown that stroke survivors are prone to recurrent illnesses due to a lack of access to rehabilitation facilities due to the pandemic. Suggestions regarding the potential for neurological rehabilitation to be taught and practiced at home [7] are given. This shows that the role of the family is vital in helping stroke survivors. Treatment for post-stroke patients should be started as early as possible. Delays will cause things that are not good and we do not expect. In addition to the treatment carried out by the medical team, the intervention of family members significantly affects the recovery process of stroke survivors. Attention and control of all activities and lifestyles are needed to avoid further strokes that are more severe.

The Health and Demographic Surveillance System (HDSS) is a surveillance system that periodically collects data related to population transitions, health status, and social transitions over a certain period. In 2014, the Faculty of Medicine UGM, in collaboration with the Government of Sleman, initiated the implementation of HDSS in Sleman Regency, called HDSS Sleman. Data collection is carried out every year. HDSS Sleman also collects data from people with a history of stroke.

A preliminary study in the form of a previous interview conducted on one of the families of stroke survivors showed that the family is very protective of stroke survivors against the threat of COVID-19, and the family is trying the best ways to prevent the transmission of COVID-19. A study to assess a person's perception of the threat of COVID-19 using mixed methods showed that with quantitative methods, 48% of people had adverse emotional reactions, and 20% thought they were vulnerable or easily exposed to viruses. There was a positive correlation between feelings and perceptions of threat. The qualitative method found 3 significant themes: a sense of shock and confusion, awareness of the new reality, and concern for him and his family [8].

Another study reported an increase in stress, anxiety, and depression as a form of the negative effect of the threat of COVID-19 on the population in China during the first outbreak and no significant reduction in anxiety and depression levels in the weeks that followed until they peaked [9].

Based on the problems described above and the preliminary studies that have been carried out

previously, it is important to research to explore the fear and anxiety of families of stroke survivors against the threat of COVID-19 in the Sleman Regency area.

METHODS

This type of research is qualitative research using a phenomenological research design. Phenomenological research aims to identify the nature of human experiences with social facts and phenomena [10]. This study is nested research in the HDSS Sleman area. It utilizes secondary data in the form of information on stroke survivors in the Depok District, Sleman Regency, as part of the Sleman HDSS population where the study was conducted. Data collection was carried out through in-depth interviews. Informant selection technique using a purposive sampling method. The research subjects were residents of Caturtunggal Village, Condong Catur Village, Maguwohardjo Village, Depok District, and Sleman Regency. The data source triangulation method was used to test the credibility of the data.

RESULTS

Overview of research sites

Depok sub-district includes Caturtunggal Village, Condong Catur Village, and Maguwohardjo Village. Data on stroke survivors who live in Depok District

comes from secondary data from HDSS Sleman, which is 29 families spread over three villages in Depok District, Caturtunggal Village, totaling 13 families. There are eight families in Condong Catur Village and eight in Maguwohardjo Village. The location of Maguwohardjo Village is not permitted for research because some Caturtunggal Villages in the Tambakbayan area (4 families) do not get permission from the RT head because of the high number of COVID-19 cases in the area. Therefore, the research process can only be carried out in Condong Catur Village and some Caturtunggal villages, which include 17 families.

Overview of research informants

The study's informants were residents of Depok District, Sleman Regency. The youngest informant was 36, and the oldest was 64. The study's informants were both men and women.

The educational background of the informants varied from Elementary School to Bachelor's (S1) education. Most informants are entrepreneurs (owners of certain small businesses), and some are homemakers. The total number of informants was 8, consisting of two men and six women. Almost all of the informants have quite deep interactions and generally have spent more than five years with stroke survivors. The health status of stroke survivors varies, but they are usually in good health and free to do activities. However, some have limited physical activity.

Table 1. Characteristics of research informants

No.	Name	Gender	Age	Education	Profession	Relationship with stroke sufferer	Health Status stroke sufferer
1	PJ	F	64	Junior high school	IRT	Wife	Still stroke
2	HS	M	40	Vocational school	entrepreneur (catering)	Biological children	Died during a pandemic (not COVID-19)
3	MG	F	62	Elementary school	entrepreneur (grocery store)	Wife	Recovering from a stroke
4	DY	F	43	Senior High School	IRT	Biological children	Died during a pandemic (not COVID-19)
5	SJ	F	54	Vocational school	entrepreneur (angkringan)	Wife	Recovering from a stroke
6	TP	F	36	Bachelor	IRT	Daughter-in-law	Recovering from a stroke
7	TR	F	42	Senior High School	entrepreneur (angering)	Biological children	Still stroke
8	S	M	45	Senior High School	Head of RT + Entrepreneur (traders in the market)	Son-in-law	Still stroke

Table 2. Themes, categories, subcategories, and codes of informant interview transcripts

Theme	Category	Subcategories	Code
The risks and pain experienced due to COVID-19	Groups who work outside the home, the elderly, and lack physical activity are at risk of being exposed to COVID-19.	At risk of being exposed to COVID-19 who are elderly and have comorbidities	The elderly are at risk of exposure. Parents have a fast COVID-19 reaction. Vulnerable to COVID-19 with internal disease (shortness of breath). COVID-19 is easy to attack people with stroke. Parents with low immunity are more susceptible to infection than young people. Stroke is vulnerable because the body's immune is low. Have comorbid symptoms so severe. Strokes that are difficult to talk about in severity because of high COVID-19. Those who have internal disease (shortness of breath). Parents/elderly need to be taken care of.
	Feelings facing the threat of COVID-19	Response to fear due to the transmission of COVID-19	Fear of contagion of COVID-19 Fear of exposure Afraid of the cost of the COVID-19 test Afraid to do a swab Just surrender Afraid to do an examination If exposed, will be ostracized People's dishonesty makes people anxious and suspicious Scared after many positive cases Can hamper the family economy

Overview of research results

The emergence of fear of the threat of COVID-19 is more influenced by experience (self/others) and aspects of the surrounding environment that feel the same threat. Referring to what is shown in Table 2, families of stroke survivors also think that stroke survivors are a vulnerable group or at risk for COVID-19. All of them showed reactions of doubt and fear of visiting health facilities, both practicing doctors, health centers, and hospitals during the COVID-19 pandemic because they felt they would be threatened with infection if they visited those health facilities because they were gathering places for all who are sick. Another study also found that people with mild/ordinary symptoms limit themselves to visiting the hospital for fear of contracting COVID-19 [11].

Treatment for patients with relatively severe strokes during the pandemic is carried out by calling family doctors for home visits. In contrast, stroke survivors with other comorbidities (diabetes mellitus)

are managed by the family to anticipate themselves (related to drug administration and blood sugar testing using personal test equipment).

An overview of the family's fear of the threat of COVID-19 in stroke survivors

The risks and pain experienced due to COVID-19

Groups who work outside the home, the elderly, and lack physical activity are at risk of being exposed to COVID-19. The results show that families of stroke survivors also think that the elderly and those who have comorbidities, such as stroke survivors, are a vulnerable group and are at risk for the threat of COVID-19 due to a decreased immune system.

“... yes, those who are at risk... those who are over 50, those who have congenital disease... are at risk... because if, for example, we often meet face to face, the

crowds can get infected and if we avoid crowds, God willing, it won't..."

"...and most of those who got COVID-19 and died, they said they had congenital disease...there were congenital accompaniments...like that (points to a neighbor's house) yesterday, the person who died had diabetes, the one next to him said he had heart disease, then the southern one said it was lung... So when I look at it, most of those who died were due to congenital diseases...who took medicine every day, right..." (DY, female, 43 years old, high school, IRT)

"...the risk is yes...the old age...because my biological parents died of COVID-19...I am the daughter-in-law of my mother here...my biological father died in Pontianak..."

"Because of what... it's so fast (reaction)... if it's a parent, the effect of the symptoms becomes more severe..." (TP, female, 36 years old, Bachelor, IRT)

"...can be susceptible huh..especially for ehh...especially stroke sufferers...that's for sure for the immune system, I'm sure it's much lower than normal, so the level of vulnerability is actually higher...and compared to normal conditions..." (S, male, 45 years old, high school, Head of RT/Entrepreneur (Trader))

Feelings facing the threat of COVID-19

The informant showed a fearful response. Studies show that fear and anxiety are high in places where the most confirmed positive cases of COVID-19 are [12].

"..yes..we are scared...but..just give up, hehehe...the main thing is maybe destiny...already arranged..." COVID-19... It will be a commotion later... well, having a chat later... it's as if it's like being ostracized..."(PJ, female, 64 years old, junior high school, IRT)

"Hmm, for example, if our mother drops her blood sugar, we will also anticipate how to raise it. I'm also worried—not because of anything; with a condition like this, it's for the mother's immunity. Yes, the family is a little more anxious. If we go to the hospital, my mother is sick, so how do you do it with your family? Anticipate yourself.

"Our families have the equipment (test equipment).. So whenever it is possible or we need it, we will take it from their place... then we will test it ourselves... we know when it goes up or when it goes down from the tool.." (S, male, 45 years old, high school, Head of RT/Entrepreneur (Traders))

"Yes...because this COVID-19 has an extraordinary effect...just want to check it...made us scared now, sis..."

"...it's hard, Ms., this pandemic, we are just afraid...afraid of getting hit, Ms.

"Yes, because gathering with a lot of people, and the puskesmas was the first goal, sis.. before going to the hospital everywhere, the first goal was to go to the puskesmas ... and yesterday I wanted the vaccine, while sitting in the ER.. "don't sit in the ER told to move.. loh nopoh?.. it's all sick brought there... my friends, just want to drink... can't... don't buy drinks anymore, don't open masks ". a friend of mine told me. That's how it is, is... there's a lot of PPE there. There's PPE being washed... I don't know how to go through it,, they said don't go through there... until that's how it is.. What's certain is that we're afraid of COVID-19, but what are we going to do? .." (DY, female, 43 yrs old, high school, IRT)

"...(stroke treatment during the pandemic) no... later at most call a doctor here.. that's the only complaint mom has a headache,.. we used to have a neighbor doctor anyway.. he now lives in Joho there.. used to be a neighbor here ...general practitioner..if the residents here are sick, they usually call Ana's doctor...so there are many suitable ones here, so when we are ill, we don't have to go anywhere, we will just have to call, later she will be here.

"...the others (neighbors) can be swabbed...the other doesn't want to....don't want to be swab because scared, until she dies... she immediately had spasms, suffocated then but for a few minutes she wasn't there...died at home..."

(TR, female, 42 years old, high school, Self-employed (Angkringan))

"At first I was afraid... but after a while it got used to it... at the beginning of the pandemic it was paradoxical, everyone was afraid... the road was lonely... everywhere was quiet... it was out and about as needed..."

"...now I don't dare to go out anymore...because it spreads easily and quickly...it is easy to spread, it spreads fast...wow that's it...that's scary...he'eh...that easy and fast...creepy..." (HS, male, 40 yrs old, SMK, Entrepreneur (Catering))

DISCUSSION

This study aims to explore the family's fear of stroke survivors against the threat of COVID-19 in the Depok District, Sleman Regency, Yogyakarta. The interview process was carried out on families with three types: families who still care for stroke survivors at home, families whose stroke survivors have recovered from stroke, and families whose stroke survivors have died in the early pandemic period (April and August 2020) and were not caused by COVID-19, provides a picture of almost the same fear of the threat of COVID-19 for stroke survivors.

Families who still care for stroke survivors who are still sick have different challenges in protecting stroke survivors, especially during the 2021 pandemic with the relatively fast rate and mode of transmission of the new variant of COVID-19, compared to families whose stroke survivors have recovered or died. Families of stroke survivors assume that the elderly and those who have comorbidities such as stroke are a vulnerable group and are at risk for illness due to the threat of COVID-19. The personal experience of the family and the surrounding environment also reinforces this. One study stated that there is a lot of evidence showing a link between non-communicable diseases and COVID-19, which can worsen health and is also associated with the possibility of it occurring in the elderly and frail population, causing death in the elderly. The data of this study show that there is a

significant correlation between non-communicable diseases such as heart disease and ischemic stroke and death from COVID-19 [13].

The reaction of fear in the form of anxiety and concern for checking during the COVID-19 pandemic at health facilities, both hospitals and health centers, was shown by the family. Families choose to call a doctor at home or anticipate on their own if the stroke survivor's condition worsens. Anticipation is done by preparing test equipment (for stroke survivors with a history of diabetes) and trying various ways so that the patient returns to normal.

Research at health facilities in Italy reported that during the pandemic, the high use of emergency facilities for those exposed to COVID-19 caused sufferers with symptoms or ordinary emergencies unrelated to COVID-19 to limit their hospital visits. This situation is caused by the patient's fear of contracting the virus in the hospital. It results in low utilization of the emergency department for common complaints and a tendency to delay consulting a specialist [11].

The study reported that there was no data on the incidence of ischemic stroke from the emergency room at a Milan general hospital (compared to an annual average of 612 new cases of ischemic stroke and a monthly average of 51 new cases) and suggested that this reduction was due to fear will be infected with the COVID-19 virus [14].

Fear of the possibility of being exposed to COVID-19 when visiting health facilities, both hospitals and health centers, to provide treatment for family members who have had a stroke with comorbidities, be it diabetes mellitus, cholesterol, high blood pressure/hypertension, need special attention from health service institutions that shelter communities with these characteristics. Data collection and preparation of work plans as an effort so that treatment for stroke survivors can still be achieved needs to be designed and implemented. It is also hoped that this will help families overcome their fear of visiting health facilities.

CONCLUSION

The fear of the susceptibility of stroke survivors when exposed to the COVID-19 virus is shown by families of stroke survivors by avoiding visits to health facilities, either Puskesmas or hospitals and choosing to anticipate themselves at home. Personal perceptions and the influence of the surrounding environment influence the family's fear of stroke survivors of the

threat of COVID-19. The fear of the families of stroke survivors must be the concern of the healthcare institutions that protect them so that treatment and health services for stroke survivors during the pandemic can still be achieved.

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