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# The Experience of Family Caregiver's in Caring for Post-Stroke Patients at Home During the Pandemic Covid-19

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## ABSTRACT

**Background:** Taking care of a family member(s) who suffers from stroke at home especially during the covid-19 pandemic time is unquestionably not easy. This study aimed at exploring the experience of family-caregivers in caring for post-stroke patients at home during the covid-19 pandemic.

**Methods:** This qualitative research employed a phenomenological approach with participants consisting of 14 family members who have been caring for post-stroke patients at home during the Covid-19 pandemic in the Pontianak City area. This research began with observation for 3 months which was then followed by interviews and FGDs. The data obtained from the results of in-depth interviews and FGDs were processed using content analysis.

**Results:** The result of his study generated 5 themes regarding the experience of family caregivers in caring for post-stroke patients at home during the Covid-19 pandemic including 1) Changes in caregiver roles, 2) engagement values, 3) spiritual values, 4) Isolation in the surrounding community, 5) The experience of situational anxiety

**Conclusions:** Considering that both stroke survivors and caregivers of post-stroke patients do not only face several problems and conditions related to stroke and stroke recovery as well as community stigma, several live scenarios are provided for them especially during the COVID-19 pandemic. Therefore, further community reintegration ought to exist in the rehabilitation where it can prepare someone who used to suffer from stroke to have ability to do self-reorganization psychologically, physically and socially.

## I. INTRODUCTION

Americans die every 4 minutes from stroke. In the US, stroke is the number one cause of disability and the fifth leading cause of death (Nayeri, 2014; Torregosa, Sada, 2018). The prevalence of stroke in 2019 was 101.5 million, with details of 77.2 million ischemic stroke, 20.7 million intracerebral hemorrhage, and 8.4 subarachnoid hemorrhage. Statistical data recorded that 610 million people died from stroke in 2020, which has increased from the previous year, 2019 (AHA, 2021; Sveriges officiella Statistics, 2021). Likewise, Oceania and Southeast Asia are the leaders of intracerebral

hemorrhage in the world and then become one of the countries with the highest stroke mortality rate as well (AHA, 2021). Furthermore, in Indonesia, one of the Southeastern countries, stroke was the leading cause of death during 2007-2017 (Institute for Health Metrics and Evaluation, 2020)

When it strikes, stroke affects the patient and related people (e.g., family) in many ways, and several studies divide the impacts into individual impacts, family impacts, and social impacts (Araújo et al., 2019; Northcott, Moss, Harrison, 2015). Additionally, Physical, psycho intellectual, and individual function, are three categorized of individual impacts resulted from a stroke disease (Bettger, 2018; Broussy et al., 2019; Karuniawati, 2017; Philp et al., 2015). In family impacts, some families feel burdened, but some of them benefit from stroke that attack one of their family members (Agianto and Nuntaboot, 2018; Gillespie & Campbell, 2011; Hesamzadeh, Dalvandi, Maddah, 2015; Karunia, 2016; Somerville et al., 2019). Finally, social impact, where a person and related environment who experience this disease experience decreased social activity, family life problems, and vulnerable relationships with friends and coworkers and other networks (Northcott, Moss, Harrison, 2015). Therefore, stroke survivors need more attention to be able to overcome this situation.

Stroke can attack people of all ages. However, the data show that the elderly is more common in these cases. According to records in 2020, 74 percent of stroke deaths occurred at the age of 70 years and over, based on this real data, those aged 70 years and over died the most as a result of stroke (90%). Only less than 4 percent of stroke survivors die under 50 years (Sveriges officiella Statistik, 2021). The condition of stroke in Indonesia as reviewed shows that the incidence of stroke in urban areas is more common. This is in contrast to the relatively small incidence in rural areas. While the prevalence of stroke patients age is 40 years and upper (Department of Health of Samarinda Province, 2017; Maharani et al., 2019; The Health Minister of the Republic Indonesia, 2018a). Indonesia is a leading country in smoking behavior in Southeast Asia which is correlated with health behaviors supporting stroke (Kulshreshtha et al., 2012). One of provinces in Indonesia, West Kalimantan-Pontianak, also has a significant number of stroke sufferers. Based on data taken from the West Kalimantan basic health data research in 2018 determined that the age group of stroke sufferers was aged 75 years and upper (54,22%), with the highest proportion of women, uneducated and most unemployed; and specially the prevalence number confirms the previous study findings of Indonesian Statistic record regarding stroke prevalence that urban population has the most strokes (The Health Minister of the Republic Indonesia, 2018b).

In early 2019, December, unexplained pneumonia first broke out in Wuhan, China which later became a global pandemic called coronavirus disease 2019 (COVID-19). Two hundred and ten countries with more than 29 million people, and 900,000 confirmed COVID-19 deaths (Nannoni et al., 2021). The WHO report data reviewed by the panel showed that 5% (95% confidence interval [CI]: 2.8-8.7%) who suffered from ischemic stroke had a risk of COVID-19 infection (Spence et al., 2020). Some literature has found that Corona virus infection (COVID-19) has an impact on neurological symptoms including stroke and other neurological diseases (Avvantaggiato et al., 2021). Stroke attacks have stroke sequelae. Almost all sequelae of stroke create disability, especially when coupled with a COVID-19 diagnosis (Frumkin & Haines, 2019; Martinez et al., 2020; Mercer, 2018; Pitthayapong et al., 2017; Richards et al., 2016). Thus, as this case inevitably occurred during a pandemic, rehabilitation services have proven the needs of post-stroke patients, regardless of conditions. During the COVID-19 pandemic, almost

all health services implemented strict health protocols (Kamalakaran et al., 2016; Qi et al., 2020). Therefore, families as caregivers for post-stroke patients must take care of themselves at home, including rehabilitation. In other cases, the demands for care from stroke caregivers with stroke added with a diagnosis of COVID-19 (Nayeri, 2014; Spence et al., 2020). The need to understand the experience of the family as a caregiver for post-stroke patients who are treated at home during the COVID-19 pandemic is of interest to researchers. The purpose of this study was to explore the experience of family caregivers in caring for post-stroke patients at home during the Covid-19 pandemic.

## II. RESEARCH METHODS

This qualitative research used a phenomenological approach, and the participants in this study were 14 family members who were caring for post-stroke patients at home during the Covid-19 pandemic in the Pontianak City area. This research began with a 3-month- observation, which then was followed by interviews and FGDs. Furthermore, the data that has been obtained from the results of in-depth interviews and FGDs was processed using content analysis. This research was conducted after obtaining ethical approval from the Ethics Committee of the Pontianak Muhammadiyah College of Nursing Number: 86/II.1.AU/KET.ETIK/III/2021

The instruments used in conducting in-depth interviews was interview guidelines developed by the researcher based on the research objectives. Some examples of main questions based on interview guidelines include 1) how have you been caring for a family member who had a stroke during the Covid-19 pandemic, 2) how did you feel when you cared for a family member who had a stroke, 3) What lessons have you learned or you get in caring for family members with strokes at home during the covid-19 pandemic.

In this study, the researcher followed the criteria to maintain the reliability of research results, which consisted of credibility, transferability, dependability, and confirmability (Farrelly, 2013). Techniques for building trust in this study were carried out as follows 1) credibility, which is parallel to validity, carried out with prolonged involvement, member checking, and persistent observation; 2) transferability, which is parallel to external validity, was carried out by purposive sampling; 3) dependability, which parallels reliability, carried out by external audits and audit trails; 4) confirmability which is parallel to objectivity carried out by external audits and audit trails.

Data were analyzed using thematic analysis techniques. According to Braun and Clarke (2006) thematic analysis consists of six stages which include verbatim and such processes as transcribing all audio recordings of interview data, coding, searching for themes, reviewing themes, defining and naming themes, and the last process is writing (Braun & Clarke, 2006). In the first stage, the researcher first wrote or recorded all the audio recorded in Indonesian and then translated them into English. Then the researcher read them back and checked the recordings as well as their transcriptions, in this case they were in forms of writings that had been typed. In the second stage, the researcher did the coding for the transcription results. This was done by identifying the data considered to be related to the research questions and then coding all data items line by line. In the third stage, after coding, the researcher then made sub-themes which were grouped into themes. The themes are then classified based on the categories that come from each code group. Finally, in the last stage, the researcher wrote all the research findings.

### III. RESULTS

The findings of this study resulted in five themes regarding the experience of caregiver-family in caring for post-stroke patients at home during the COVID-19 pandemic which consisted of 1) changes in caregiver roles, 2) engagement values, 3) spiritual values, 4) ostracized from society and its surroundings, 5) the experience of situational anxiety.

#### Theme 1: Changes in caregiver roles

Caring for parents who have a stroke during the Covid-19 pandemic brought several changes to family members, especially female family members who take care of their mothers with strokes at home during Covid-19, as shown below:

*"... in the past, everything was done by mom but now since mom is sick, everything is done by me, such as cooking vegetables, washing clothes, packing, basically I'm the one who does all the housework" (P1, 30 yo)*

*"I'm more independent because I don't depend on my parents anymore since mom has been sick, then I took over all the housework instead of mom, it's impossible for my father to do the work..." (P8, 25 yo)*

*"Besides taking care of my husband who has a stroke, I also have to work to replace my husband's role as the backbone of the family because if I expect what is given by my children, it's not enough..." (P10, 38 yo)*

*"...since my husband has had a stroke, he cannot work anymore so I have to work to earn a living to meet my children's daily needs and tuition fees" (P12, 31 yo)*

Unlike a husband who is the main caregiver for his wife who has had a stroke, the husband said that he has to take care of his sick wife alone because he is alone at home as shown in this transcription below:

*"... like it or not, I myself, the only one, who takes care of my wife at home, clean her body, help her urinate or defecate, and I also have to cook in the kitchen because there are no children living at home" (P5, 48 yo)*

#### Theme 2: Engagement Values

Several participants revealed that caring for sick parents is a child's duty and obligation to both parents, as stated by some of the following participants:

*"...it's the child's job to take care of sick parents, sir, even though we sometimes get tired when coming home from work, but like it or not, because my parents live with me, so I have to take care of her, no matter what her illness is." (P13, 22 yo)*

*"Who else is taking care of our stroke mother during this pandemic? if not us as his children. So, we can be closer to our parents, and as the evidence given to our children (i.e. an example) of our devotion to the parents who have raised us, it is obligatory for us to take care of them when they are sick like now, Sir..." (P11, 30 yo)*

In contrast to the participants who took care of their partners who have a stroke during the COVID-19 pandemic. Some couples, especially wives, feel that taking care of their husbands when they are sick is a wife's obligation to her husband, as stated by the following participants:

*"As a devotion to my husband when he is sick, I can take care of him and continue to fulfill my obligations as a wife because I love him not only when he is healthy but also when he is sick, it is my duty to take care of him..." (P6, 33 yo)*

Run-on (ETS)

*"...(it is like) testing my loyalty to stay with my husband until the end of his life, and I take care of him until he recovers, especially during this Covid condition, of course I will be by his side because I am his wife and it is my duty to take care of my spouse..." (P7, 52 yo)*

*"...because it is my duty and obligation as a wife, I take the time to continue to care for my husband who is sick even though I am exhausted after coming home from work, because I understand that, as a wife, I have to take care of my husband, my husband, no matter how tired I am..." (P12, 31 yo)*

### **Theme 3: Spiritual values**

Participants who are Muslim are of the view that caring for sick parents is a practice for a child to reach heaven if she/he takes care of her/his parents sincerely and patiently, as stated by some of the following participants:

*"...who else will take care of the parents if it's not me, the child, after all, it's my duty as a child to take care of my sick mother and this can be my practice to get my reward and heaven..." (P13, 22 yo)*

Run-on (ETS)

*"...I have to be patient when taking care of mom, if not, I won't be sincere at the end. Allah will surely reward me for taking good care of my parents as well as giving me health and ease of working..." (P8, 25 yo)*

*"...taking care of my mom who has a stroke is part of (faith) worship for me, so I will get a reward, hopefully by taking care of my mom I can get heaven when I die (P2, 25 yo)*

Furthermore, there were also participants who said that the wisdom gained from giving care for their elderly with stroke at home during the covid-19 was that they became more obedient in worship and were closer to God by practicing their faith duty, as expressed by the following participants:

*"Every time I pray, I always pray that Allah will heal my wife who has a stroke, and I will also be also given health during taking care of her..." (P3, 29 yo)*

Run-on (ETS)

*"During prayers I do not forget to pray for my wife to get well soon, and we who take care of her would be kept away from the dangers of the Covid-19 virus. Besides doing prayers, I also do more fasting and donation so that Allah grant our prayers (P5, 48 yo)*

#### Theme 4: Isolation from society and its surroundings

Some participants who provided care for family members with strokes during the Covid-19 pandemic also met unpleasant experiences from their neighbors and local residents due to having and taking care of family members with strokes at home, as stated by the following participants:

*"Every time I pass in front of a neighbors' houses, they must quickly enter their house and the door is closed, even though I just pass by, not wanting to go to their house..."*  
(P14, 47 yo)

*"...the women in this alley, when they saw me coming from afar, they immediately avoid me as they were afraid that I would carry the virus and transmit the Covid-19 virus to them (P6, 33 yo)*

*"When I leave the house, my neighbors living on left and right of my house go straight into their house, they are really afraid of me, so we are not comfortable with this situation, they don't even want to greet us at that time..."* (P3, 29 yo)

#### Theme 5: Experiencing Situational Anxiety

Several participants revealed that they felt anxious when providing care to a family member who had a stroke during the Covid-19 pandemic. This feeling arises because of concerns, in case, that stroke sufferer had been confirmed to have Covid-19. So that if she/he dies, they must follow the burial protocol set by the government as stated by the following participants:

*"...there is a worry, what if my wife suddenly catches Covid and dies and has to be buried following the established protocol, it's a shame that the children can't see their mother anymore" (P5, 48 yo)*

*"Frankly speaking, as the children we are worried, especially during this pandemic, as my mom has a stroke. It is obvious that there may be a risk of getting COVID-19. So, we are worried what if she has to be taken to the hospital, and later due to the covid she might then die, and we children can't see her anymore..."* (P1, 30 yo)

*"As for me, I am afraid that I will bring the Covid-19 virus home and transmit it to my mother who has had a stroke. So, it would be a shame if because of me, for example, my mother caught Covid-19 and had to be isolated in a hospital, for example (P11, 30 years)*

Table 1. Characteristic of participants

Participants	Age (Years)	Sex	Occupation	Education Level	Role
Partisipant 1	30	Female	Private	Bachelor 's degree	daughter
Partisipant 2	25	Female	private	Bachelor 's degree	daughter
Partisipant 3	29	Male	private	Bachelor 's degree	husband
Partisipant 4	26	Female	private	High School	daughter
Partisipant 5	48	Male	retiree	Bachelor 's degree	husband
Partisipant 6	33	Female	Civil Servant	Bachelor 's degree	wife
Partisipant 7	52	Female	retiree	High School	wife
Partisipant 8	25	Female	private	Bachelor 's degree	daughter
Partisipant 9	45	Female	Civil Servant	Bachelor 's degree	wife
Partisipant 10	38	Female	Housewife	High School	wife
Partisipant 11	30	Female	private	Bachelor 's degree	daughter
Partisipant 12	31	Female	Civil Servant	Bachelor 's degree	daughter
Partisipant 13	22	Female	students	Bachelor 's degree	daughter
Partisipant 14	47	Female	housewife	High School	wife

#### IV. DISCUSSION

One of the impacts of the COVID-19 pandemic for stroke patients is the length of hospitalization. It was found that based on data analyzed of several studies more than 2000 hospitals experienced a decrease in length of stay. In particular, the length of stay for stroke patients is >4 days during the COVID-19 period. (Burns et al., 2022; Srivastava et al., 2021). Therefore, the choice of treatment for stroke patients is home setting or hospice. Unfortunately, in some conditions stroke caregivers and stroke survivors have only acquired fewer skills for stroke care. In addition, outpatient therapy centers and home health cares are limited in the community (Sama et al., 2021; Srivastava et al., 2021). Hence, home is the main choice for follow-up care, especially during the COVID-19 pandemic. Consequently, there are more duties, responsibilities, and needs from a spouse, a parent, or a family member with the illness that cause the changing the role of caregivers. A change in role of a caregiver means a significant change in the caregiver's response from day to day or special moment, for examples, teachers, advocates, personal



officers, personal principals, personal officers and advocates, entertainment directors, movement facilitators, friends, administrators, health care providers and personal trainers are some of the differences as a result of changing caregiver roles (AARP, 2019; Dula et al., 2020; Jennifer L. Rowe, 2021).

A study carried out in Brazil found thirty-eight percent of stroke survivors with hemorrhagic stroke were dependent on their caregivers at discharge, after 1 to 2 years were 16% dependent, and 14% dependent 3 years later. The number is smaller than patients with subarachnoid hemorrhage who was 19% dependent at discharge, and 45 after 1 to 3 years, in Brazil. Functional Dependence (FD) was estimated at 120 stroke patients every year (De Campos et al., 2017). Almost all caregivers who provided care for stroke survivors are informal or unskilled caregivers. Informal caregiver is someone who provides unpaid care with for their work, a potential person with negative consequence, who must deal with all types of demand care, a lot of burden, and worship (Revenson et al., 2016; Zarzycki & Morrison, 2021). Family members serve as stroke caregivers have main caring-tasks for recovery and keep a life for patients with stroke. In another case, someone who is a stroke caregiver must be prepared to give the cares or to experience the stroke impacts toward her or his life. Several literatures were discussed and observed for some factual data that promote the preparedness of stroke caregivers because stroke cases require long-term care, and there are only a small proportion of stroke patients without comorbidities related diseases. In other studies, too, found some of the effects of being a stroke caregiver or unwillingness to bother others made stroke survivors use a formal caregiver (Garnett et al., 2022; Haley et al., 2019; Lobo et al., 2021).

Several studies claim individual and social behavior as a result of religious belief. In Indonesia, eighty-five percent of the population is Muslim, around 255 million of the total population is Muslim (Mahyarni et al., 2018). Accordingly, the main spiritual value in a Muslim is "taqwa"—some ways of religious practice to be close to God and others. Therefore, it can motivate a person to carry out an alternative way for her or his actions in terms of providing cares for a family member with stroke and in this study this principle exists in almost caregivers. Spiritually, taqwa is related to human experience with oneself, relationships, love, involvement, favors, togetherness, or the state of health through which human experience increasing spiritual values. (Mahyarni et al., 2018; O'Callaghan et al., 2019; Razak, 2020).

Community stigma is usually based on the conditions of an individual who has mental disorder or chronic neurological problems. In this case, the most common neurological defect is caused by stroke (Pang, 2013; Sarfo et al., 2017). Permanent disability due to stroke conditions makes stroke sufferers lose their normal and responsible roles. Moreover, the impacts are not only experienced by a stroke survivor himself, but also family members in general and particularly the caregivers. The caregivers are loaded with several new tasks and responsibilities for giving cares for their family member with stroke, which reduces their community activities. This situation also undermines the public perception that someone who returns home from the hospital is a COVID-19 patient. In this case, stigma in society emerges and correlates with clinical, psychosocial, and demographic characteristics of some people in society (Deng et al., 2019; Obembe et al., 2013; Sarfo et al., 2017).

The relationship between COVID-19 and the incidence of stroke associated with coagulopathy, endotheliopathy and antiphospholipid antibodies increases the likelihood of death and critical illness (Goshua et al., 2020). Another study by Mao and colleagues

claimed that 0.5% of 221 COVID-19 positive patients had cerebral hemorrhage and 5% had ischemic infarction (Mao et al., 2020) The specific response that increases anxiety is called situational anxiety; in this case it is related to the COVID-19 pandemic and the incidence of stroke, both of which have links in the pathobiological system. (Taneasa White, 2022). Some literature depicts that anxiety has a relationship with objective and subjective burdens. Most stroke caregivers find the burdens on care activities, as affirmed by some research conducted in Asia (Pérez-Cruz et al., 2019; Wang et al., 2021).

## CONCLUSIONS

Several life scenarios are provided for both stroke survivors and stroke caregivers, especially during the COVID-19 pandemic. They do not only face the problems and conditions related to stroke and stroke recovery, but also have to accept the stigma of society. Therefore, further community reintegration must exist in stroke rehabilitation which prepares someone who has had a stroke to be taught how to self-reorganize psychologically, physically, and socially.

## ACKNOWLEDGEMENT

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**Sp.** This word is misspelled. Use a dictionary or spellchecker when you proofread your work.



**Sp.** This word is misspelled. Use a dictionary or spellchecker when you proofread your work.



**S/V** This subject and verb may not agree. Proofread the sentence to make sure the subject agrees with the verb.



**Sp.** This word is misspelled. Use a dictionary or spellchecker when you proofread your work.



**Prep.** You may be using the wrong preposition.



**Sp.** This word is misspelled. Use a dictionary or spellchecker when you proofread your work.



**Sp.** This word is misspelled. Use a dictionary or spellchecker when you proofread your work.



**Missing ", "** Review the rules for using punctuation marks.



**Proper Nouns** You may need to use a capital letter for this proper noun.

