



## RESEARCH ARTICLE

# REVISED Roles and Problems of Stroke Caregivers: A Qualitative Study in Yogyakarta, Indonesia [version 2; peer review: 2 approved]

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## Abstract

**Background:** Caregivers play a central role in post-stroke patients' care. However, the role of and problems managed by caregivers have not been widely studied, particularly in Indonesia. This study aims to explore the roles and problems of caregivers in post-stroke patients' care.



**Method:** This was a qualitative study. Seven caregivers of post-stroke patients from the homecare clinic of Dr Sardjito General Hospital were purposely selected during January 2017 to June 2018. Focus group discussions were conducted to explore the roles and problems of caregiving.



**Results:** Themes related to caregivers' roles were: connecting patients with medical personnel and other family members, maintaining patients' health conditions by fulfilling basic needs and assisting rehabilitation, as well as maintaining patients' psychological conditions by encouraging conversation, telling jokes, or recreation. On the other hand, themes related to caregivers' problems were: lack of knowledge caused by education inadequacy, underappreciated and unconcerned family, suboptimal service including limited physiotherapy and pharmacy resource, unthorough administration, lack of communication, physical limitations, and burnout, as well as uncooperative patients.

**Conclusions:** Caregivers play essential roles as communicators and help to maintain patient's health conditions. Common problems are related to a lack of knowledge about strokes and a lack of attention from family. Further research to study the effects of these findings on the quality of life of both patient and their caregiver, as well as how to

## Open Peer Review

Reviewer Status  

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handle the caregiver issues should be investigated.

### Keywords

caregiver, role, problem, homecare, stroke, post-stroke care

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**REVISED Amendments from Version 1**

In the new revised version, we have refined some statements based on the reviewers' suggestions, such as imply the definition of caregivers particularly in Asian population, re-organize the paragraph and cite the quote after each point in order to improve the flow of writing, and revised the conclusion related to suggestion for future study.

**Any further responses from the reviewers can be found at the end of the article**

**Introduction**

Caring for stroke survivors is a long-term experience that could influence a person's quality of life.<sup>1</sup> In Indonesia, stroke has been the leading cause of death and disability for ten consecutive years (2009-2019).<sup>2</sup> Stroke, mainly affecting the elderly, may cause lifelong immobility, speech and communication problems, cognitive decline, urinary/fecal incontinence, and behavior changes that generally need long-term care.<sup>3,4</sup> Therefore, stroke survivors become dependent on their caregivers, who take-on numerous roles and duties.<sup>3,5</sup>

Caregivers can be either formal or informal caregivers.<sup>6</sup> Formal care is delivered by professionals, such as nurses, physiotherapists, or speech and occupational therapists. Informal caregivers can be paid or unpaid. Unpaid informal caregivers are family members, friends, or relatives, meanwhile paid informal ones are domestic helpers or trained individuals.<sup>6</sup> Caregiving services can be provided in a home-based setting, a rehabilitation facility, or a nursing home.<sup>7</sup> In Asian population, the responsibility of caring the post-stroke patients mostly relies on family members, particularly the spouse or offspring who can provide caregiving in home-bound setting.<sup>8</sup>

Caregivers play a central role in post-stroke patients' care. A substantial amount of care, particularly to perform the activity of daily living, is essential for stroke survivors to improve their functional status. Therefore, caregivers are recommended to be involved in post-stroke patients care to improve the quality of patient management.<sup>7</sup>

Currently, there are vast studies related to the experiences of caring for post-stroke patients. However, the role and problems managed by the caregiver while caring for post-stroke patients in Indonesia have not been widely studied. Accordingly, this study aims to explore the roles and problems of post-stroke caregivers in Indonesia.

**Methods****Study design**

This was a qualitative study to contextually explore a range of experiences and perspectives, not to seek an agreement. We used a grounded theory approach<sup>9</sup> to identify initial themes and categories which describe the roles and problems of caregivers for post-stroke patients.

**Sample and recruitment**

We recruited caregivers from the homecare clinic of Dr Sardjito General Hospital during January 2017 to June 2018, using purposive sampling. Inclusion criteria were: (1) family caregivers or a domestic helper, who caregiving a post-stroke patient with any level of disability; and (2) providing care for  $\geq 1$  year. We sent a checklist of the eligible criteria to the homecare clinic. Staff at the homecare clinic subsequently provided us with potential participants' phone numbers with their consent. We contacted the potential participants through telephone calls to invite them to the study. A focus group discussion was scheduled after receiving confirmation of their participation. A total of seven caregivers were included in this study. Two caregivers refused to participate in the study due to personal reasons.

**Data collection**

Data were collected by conducting a focus group discussion (FGD) on 21 July 2019. The research team developed an interview guide which had been further transformed into several questions to be addressed in the discussion. The discussion was led by a moderator (the second author HDAW), assisted by a note-taker and an assistant who documented the discussion. The first author (PM, a senior neurologist) was also present during the discussion to supervise and guarantee that the discussion went effortlessly. The moderator (interviewer) was a male senior neurology resident who had basic training skills of FGD. He did not have any relationships with the participants and the participants knew him as a neurology resident who had interest in research related to stroke caregivers.

Participants' demographic data were collected at the beginning of the discussion, along with that of their care recipients' (post-stroke patients). These data included age, sex, education level, main occupation, relationship with post-stroke patient, and years of caregiving. The discussion began with a broad central question regarding the caregivers' knowledge

about stroke followed by probing and further questions related to roles and problems of caregivers. The discussion was held in a quiet and comfortable closed room (workplace) for approximately 120 minutes. It was carried out once and there were no repeat sessions.

### Data analysis

All discussions were tape-recorded and transcribed verbatim in Bahasa Indonesia. Data analysis began immediately after the discussion to identify ideas for generating categories. The semantic contents were separated and coded. Following a grounded theory approach, constant comparative analysis was used to compare data and open coding determined core categories. Identical codes were further grouped into categories to identify the main themes and subcategories.<sup>3</sup> **QDA Miner Lite version 2.0.6 software** was used to analyse the transcript and assist the coding process. The coding was further reviewed by two investigators (PM and HDAW) to establish that codes were data-driven. Any differences were discussed until consensus was reached. The full transcript was not returned to participants for comment.

### Ethical consideration

The study protocol received ethical approval from the Medical and Health Research Ethics Committee (Ethical approval reference number: KE/FK/0800/EC/2020) at the Faculty of Medicine, Public Health, and Nursing, Universitas Gadjah Mada, Yogyakarta, Indonesia.

### Consent

All participants were given a brief explanation of the research and gave written informed consent in accordance with the Declaration of Helsinki.

### Results

We enrolled seven caregivers; all subjects were female with a median age of 36 years (interquartile range [IQR] was 17). All had home-based responsibilities and half of them had less than 5 years of caregiving experience. These caregivers managed five post-acute stroke patients. Patients' median age was 72 years (IQR was 14). Four (57.2%) of the caregivers had higher education while the other three (42.8%) had secondary education.

Five caregivers (71.4%) were full-time carers, while two others (28.6%) still had another job. Most of the caregivers (57.2%) were professional caregivers, while the other three (42.8%) were family members. One of the caregivers (14.2%) had been working as a caregiver for more than 10 years, two caregivers (28.6%) had been working for 5-10 years, and four others (57.2%) less than five years. The basic characteristics of the participants are depicted in [Table 1](#).

After the discussion had been transcribed, 18 coding variables related to the roles of the caregiver for the post-stroke patient emerged from qualitative analysis. These 18 variables were reduced to six categories: communication, basic needs

**Table 1. Characteristics of participants and post-stroke patients.**

Characteristics		Caregivers (n = 7)		Post-stroke patients (n = 5)	
		Median (min-max)	n (%)	Median (min-max)	n (%)
<b>Age (years)</b>		36 (27-67)		72 (66-85)	
<b>Sex</b>	Male				1 (20%)
	Female		7 (100%)		4 (80%)
<b>Education level</b>	Higher education		4 (57.2%)		2 (40%)
	Secondary education		3 (42.8%)		3 (60%)
<b>Main occupation</b>	Caregiver		5 (71.4%)		
	Other		2 (28.6%)		
<b>Relationships with post-stroke patients</b>	Family		3 (42.8%)		
	Professional caregiver		4 (57.2%)		
<b>Years of caregiving</b>	<5 years		4 (57.2%)		
	5-10 years		2 (28.6%)		
	>10 years		1 (14.2%)		

**Table 2. Categories and themes of the role and problem of caregiver.**

	<b>Themes</b>	<b>Subthemes</b>
<b>Caregivers' roles</b>	<b>Communication</b>	Communication
	<b>Patients' health</b>	Basic needs
		Rehabilitation
		Complications
		Responsibilities
<b>Psychological</b>	Psychological	
<b>Caregivers' problems</b>	<b>Knowledge</b>	Knowledge
	<b>Family support</b>	Family support
	<b>Service limitation</b>	Resources of limitation
	<b>Communication</b>	Lack of communication with medical personnel Communication problems with patient
	<b>Physical and mental limitation</b>	Treatment refusal Fatigue (burnout)

fulfillment, rehabilitation assistance, complication prevention and management, responsibility of patient’s condition, and maintenance of patient’s psychological condition. Furthermore, these six categories were reduced into three subthemes: communication, physical health, and patient’s psychology (Table 2).

A total of 28 codes which related to physical activity were identified which were then reduced into seven categories: knowledge, family support, limited resources and facilities, lack of communication with medical personnel, communication problem with patient, refusal to treatment, and fatigue (burnout). These seven categories are further reduced into five major subthemes: knowledge, family support, sub-optimal service, communication, as well as physical and mental limitation (Table 2).

**Discussion**

**Roles of caregiver: communication**

Caregivers act as a communicator between the patient or family and medical personnel, or the patients and their family. Caregivers connect communication between the patient and people involved in the patient’s management including doctors, psychologists, nurses, and therapists. This role serves as an important aspect of patient care, and also be integrated as a guideline for adult stroke rehabilitation and recovery.<sup>7,10</sup> Therefore, good communication skills are necessary for caregivers.<sup>11</sup>

An example of this role can be seen in the following quote:

*“... I have all the nurses’ contact numbers and mmm... what is it called... doctors’. And usually, if there is any problem... last night, for instance, she was using an urinary catheter and also a diaper. However, when I checked it, the diaper had been full with urine. In the morning, I sent text messages to a nurse and reported it: ‘This blah blah blah, please check the catheter as it may be leaking...’” (Participant 6)*

**Roles of caregiver: maintaining patients’ health**

Caregivers as the people who daily assist patients’ activities, hold responsibility for patients’ health care. Caregivers provide basic needs fulfillment and rehabilitation processes, as well as prevention and management of complications.<sup>7,11</sup>

For providing basic need fulfillment, caregivers help patients with disabilities in need of self-care and mobility such as feeding, bathing or showering, toileting, dressing, grooming, walking, and transferring.

This quote below is an example from participant about this role:

*“... within a day, our services are bathing, when it is eating time we feed them, and.. usually Mr M is simple, after bathing we feed him via PEG...” (participant 4)*

Caregivers also monitor the sleep pattern of their patients and help them to have good and adequate sleep.<sup>11,12</sup>

We can see an example of this role in this quote:

*“... yes, I stand by for 24 hours. At night I sometimes sleep next to him, to supervise him ...”* (participant 6)

During rehabilitation, caregivers also play a role in assisting rehabilitation processes by giving additional physiotherapy services at home. This is in accordance with the rehabilitation recommendations which state that families and caregivers are involved in determining the goals and implementation of post-stroke patient rehabilitation.<sup>10</sup>

Role of caregiver in helping rehabilitation can be seen in this quote:

*“... besides visiting physiotherapists in a hospital or inviting them to do home care services, in the morning and afternoon we usually have short additional physiotherapy session, only several minutes, just to stretch some muscles ...”* (participant 1)

Furthermore, caregivers play essential roles in preventing and managing complications that may eventually develop. This role is in accordance with a previous study which found that caregivers can help reduce the incidence of post-stroke complications.<sup>13</sup> However, the study above used a formal training program for caregivers which was too impractical to be implemented in this study. The importance of training and education for caregivers is also supported by other studies that showed a reduction in complications through providing education programs to caregivers.<sup>14</sup>

This role can be seen in the following quote:

*“... because my mother is ee .. her mobility is very limited, thus I need to feeding her using feeding tube. Other than that, what is it called? Catheter? Yes, a catheter! My mother is prone to urinary tract infection due to the catheter. Hence, sometimes if this infection develops, I have to... really have to do this, um ... to keep it clean...”* (participant 7)

Based on the above discussion, it can be observed that maintaining the good health of post-stroke patients is the responsibility of the caregiver. This is in accordance with prior studies which stated that there are major changes in the responsibilities of families caring for post-acute stroke patients.<sup>15-17</sup>

This can be elaborated with the quote from one of the interviewees below:

*“... this is my responsibility that she is completely dependent on us ... so we take care of her like 'because she is already completely dependent on us, so whatever happens to her, in my mind, it counts on us'...”* (participant 6)

### Roles of caregivers: maintaining patients' psychological condition

Caregivers spend a considerable amount of time engaging with patients and contribute to maintaining patients' psychological conditions.<sup>14</sup> Based on the discussion, it was found that the caregivers help in maintaining patients' psychological condition by telling interesting stories, joking, or doing recreational activities. This can be seen in the following statement:

*“... especially what we maintain is stabilitation of his mood. If he is happy, maybe mm... at least it doesn't worsen his condition ...”* (participant 5)

The role of caregivers in maintaining patients' psychological health conditions is important in preventing depression in post-acute stroke patients. Depression is one of the most common complications of stroke.<sup>18</sup> Caregivers also have a great influence on the development of the patient's psychological condition and the prognosis.<sup>19</sup>

### Caregivers' problems: lack of knowledge

After conducting the FGD, it was found that one of the problems in post-stroke patient care is caregivers' lack of knowledge. Caregiver illiteracy on stroke was clearly seen during FGD. When the caregivers were asked 'what is stroke', one of them answered:

*“... I actually don't know a thing about stroke, the definition and how ...”* (participant 6)

The other caregivers stated that they need to be equipped with some knowledge because for example, sometimes caregivers are involved in decision-making. However, they feel that they do not have sufficient knowledge to make a

decision. This results in decision-making delay. The caregivers also feel that knowledge about medication and treatment is important. However, the information given to them by medical personnels is also limited. To overcome their lack of knowledge about stroke, they searched the information from other sources. However, the information obtained is said to be inaccurate, as in the statement below:

*"... sometimes it is confusing, you know. For example, in stroke management, some sources said it is okay to do acupuncture, some other said it's not recommended, but... it's varying and confusing..."* (participant 2)

Lack of caregivers' knowledge can be a weak point in post-stroke patients care. There have been many studies which stated that one of the important modalities that a caregiver must have is knowledge.<sup>7,20,21</sup> In addition, it is recommended that the process of decision-making and treatment planning should involve both the family and the caregiver.<sup>7,22</sup>

### Caregivers' problems: underappreciated and unconcerned family

During the discussion, it was found that the family was not prepared for an emergency situation. This can delay early patient management. Meanwhile, some interviewees, domestic helpers being as informal caregivers, did not dare to take action before instruction had been given or a decision was made by the family, even though the patient was in an emergency condition. This occurred because the caregiver was afraid of being blamed, which can be seen in the following statement:

*"... we are afraid that later we will be blamed. I've experienced that. It's like 'that's to bold', or in Javanese 'kok wani-wanine (how dare you?)', even though we already did our best..."* (participant 3, a domestic helper)

Another caregiver said that she had been scolded when she encountered similar situation, like in the phrase below:

*"Even got scolded"* (participant 3, a domestic helper)

Moreover, the family did not give enough appreciation to the caregivers.

*"no respect from the family"* (participant 2, a domestic helper)

Lack of support by the family becomes a burden for the caregiver. Furthermore, the lack of family support in post-stroke patients care may reduce the quality of patient care. Family support has an important role in the patients' quality of life.<sup>23</sup>

### Caregivers' problems: suboptimal service

The main obstacle felt by the family is the lack of personnel or facilities offered by the home care unit. The interviewees stated that due to limited physiotherapy facilities and resources, the interviewees sought additional personnel from other resources. In addition, there were also some difficulties in getting the prescribed medication.

We also found that results of laboratory test delivered to family or caregiver were taking too much time. There was also a case of mistaken identity of a test result which was commented on by saying:

*"I think it could be a fatal mistake"* (participant 7)

They also expressed problems in unthorough administration. These experiences can be seen in the following quotes:

*"... I feel that the number of the physiotherapy sessions is not enough, but I know that they are really busy. We divide the resources, that's why we add from the third party..."* (participant 5)

*"... sometimes I'm confused, for example, the doctor said, 'Ma'am, the lab result is good', 'which lab result, doc? I think it's been a while since the last lab checks' ..."* (participant 6)

*"The administration, I think, still have many rooms for improvement ... Some things have been claimed, have been written, but then written again ..."* (participant 7)

Limited resources become a challenge itself because it raises the gap between the standard of care and real-world capacity of service, ranging from prevention to post-acute care.<sup>24</sup>

### Caregivers' problems: lack of communication

Perceptions that were obtained from the caregivers were that there was a lack of communication between medical personnel causing uncollaborative patient management. They stated that this caused the patient's treatment to be time-consuming. Poor communication is associated with less effective services.<sup>7</sup>

The problems above can be seen in the following quote:

*"... for example, the physiotherapist came and asked about the patient's development, then I explained 'Oh she is blah, blah, blah', 'Okay, I will report it to the doctor'. Later, the doctor will come empty-handed ... seems like uninformed. That is what sometimes makes us disappointed ..."* (participant 7)

Apart from communication problems with medical personnel, we also found that communication problems with patients became a burden for the caregiver. This is especially experienced with patients who have communication disorders. In long-term care setting, caregivers' anxiety rates have decreased. Nonetheless, caregivers' depression rates and burdens are still high.<sup>25</sup>

This was an example which expressing this problem:

*"...after her second stroke she really was deteriorated, we didn't know whether she still recognized us or not because there were no response at all from her, she was only staring but it's a blank stare..."* (participant 7)

### Caregivers' problems: physical limitations and burnout

Based on the FGD, one of the obstacles in post-stroke patients care was patients' refusal of treatment. The caregivers thought the patient's morale, pain, and burnout were the causes of the refusal. Apart from the patient side, caregivers also face physical and mental burnout.

Depression is one of the complications that often occurs in patients with a history of stroke.<sup>18</sup> Periodic examinations or screening related to depression in the patients and their caregivers by their doctor is recommended.<sup>7</sup> In addition, the deteriorating psychological condition of the patient is a heavy burden for the caregiver.<sup>20</sup> Anxiety and depression while caring the stroke patients are related to the caregivers' burden.<sup>26</sup>

Long working hours, quality of patient health, stroke severity, and level of patient dependency are factors associated with caregiver's burnout.<sup>27</sup> Other studies have shown that a high need for care is also a factor that influences caregiver's burnout.<sup>28</sup> Moreover, the emotional condition of the patient also affects caregiver's burnout.<sup>29</sup> The description of this problem can be seen in the following quote:

*"... during speech therapy, she persistently refused the therapy. The therapy ... at that time, it was from ... the speech therapy from Sardjito Hospital. When the therapist came, she pretended to sleep, and later after the therapist had come home, she woke up. She constantly refused it, she kept looking away. 'Ma'am, the therapist is coming ...' she insisted she did not want it. For communication, she responded, but she refused the therapy..."* (participant 7)

This study has several limitations. First, the caregivers in this study were recruited from one medical center, and the sample size was small. Second, our findings might not be generalized to non-Asian countries as our participants were recruited in Indonesia which has collectivist backgrounds.<sup>30</sup> Third, we did not distribute the transcription to the caregivers for verification, thus it may lead to misinterpretation. Finally, all the caregivers in our study were female which may cause differences in caregiving experiences and lead to different roles and problems. Future study can be conducted with male caregivers to capture holistic understanding of caregivers' role and problems.

### Conclusions

Caregivers play an essential role in connecting patients with medical personnel and other family members, as well as maintaining the patient's physical and psychological condition. Meanwhile, caregivers face the problems of lack of support from patients' family, lack of knowledge, suboptimal service, lack of communication and caregivers' burnout. Further research to study the effects of these findings on the quality of life of both patient and their caregiver, as well as how to handle the caregiver issues should be investigated.

### Data availability statement

#### Underlying data

Zenodo: Roles and problems of stroke caregivers: A qualitative study in Yogyakarta, Indonesia. <https://doi.org/10.5281/zenodo.4716264>.<sup>31</sup>



The project contains the following underlying data:

- English Translated Transcript-Edited-Final.doc (an English translation of the focus group transcript).

### Reporting guidelines

Zenodo. Roles and problems of stroke caregivers: A qualitative study in Yogyakarta, Indonesia. <https://doi.org/10.5281/zenodo.4729367>.

The project contains the following reporting checklist:

- COREQ\_checklist.pdf

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### Author contributions

Muhrodji P: writing-original draft preparation, conceptualization, methodology, formal analysis; Wicaksana HAD: data curation, investigation; Satiti S: supervision, validation; Trisnantoro L: conceptualization, supervision, validation; Setyopranoto I: conceptualization, supervision, validation; Vidyanti AN: visualization, validation, writing-review & editing.

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### References

- Lynch EB, Butt Z, Heinemann A, et al.: **A qualitative study of quality of life after stroke: the importance of social relationships.** *J Rehab Med.* 2008; **40**: 518–523.
- Institute for Health Metrics and Evaluation: *Global Burden of Disease: Indonesia.* 2020.
- Tseng C-N, Huang G-S, Yu P-J, et al.: **A qualitative study of family caregiver experiences of managing incontinence in stroke survivors.** *PLoS One.* 2015; **10**: e0129540.  
[PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
- Virani SS, Alonso A, Benjamin EJ, et al.: **Heart disease and stroke statistics—2020 update: a report from the American Heart Association.** *Circulation.* 2020; **141**: e139–e596.  
[PubMed Abstract](#) | [Publisher Full Text](#)
- King RB, Ainsworth CR, Ronen M, et al.: **Stroke caregivers: pressing problems reported during the first months of caregiving.** *J Neurosci Nurs.* 2010; **42**: 302–311.  
[PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
- Pucciarelli G, Ausili D, Rebora P, et al.: **Formal and informal care after stroke: A longitudinal analysis of survivors' post rehabilitation hospital discharge.** *J. Adv. Nurs.* 2019; **75**: 2495–2505.  
[PubMed Abstract](#) | [Publisher Full Text](#)
- Duncan PW, Zorowitz R, Bates B, et al.: **Management of adult stroke rehabilitation care: a clinical practice guideline.** *Stroke.* 2005; **36**: e100–e143.  
[PubMed Abstract](#) | [Publisher Full Text](#)
- Omar O, Aziz AFA, Ali MF, et al.: **Caregiver Depression Among Home-Bound Stroke Patients in an Urban Community.** *Cureus.* 2021; **13**.  
[Publisher Full Text](#)
- Corbin J, Strauss A: *Basics of qualitative research.* 3rd ed. Thousand Oaks, CA: Sage; 2008.
- Winstein CJ, Stein J, Arena R, et al.: **Guidelines for adult stroke rehabilitation and recovery: a guideline for healthcare professionals from the American Heart Association/American Stroke Association.** *Stroke.* 2016; **47**: e98–e169.  
[PubMed Abstract](#) | [Publisher Full Text](#)
- Lau DT, Kasper JD, Hauser JM, et al.: **Family caregiver skills in medication management for hospice patients: a qualitative study to define a construct.** *J Gerontol B Psychol Sci Soc Sci.* 2009; **64**: 799–807.  
[PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
- National Academies of Sciences Engineering and Medicine: *Families caring for an aging America.* Washington DC: National Academies Press; 2016.
- Pitthayapong S, Thiangtam W, Powwattana A, et al.: **A community based program for family caregivers for post stroke survivors in Thailand.** *Asian Nurs Res (Korean Soc Nurs Sci).* 2017; **11**: 150–157.  
[PubMed Abstract](#) | [Publisher Full Text](#)
- Zhang L, Zhang T, Sun Y: **A newly designed intensive caregiver education program reduces cognitive impairment, anxiety, and depression in patients with acute ischemic stroke.** *Braz J Med Bio Res.* 2019; **52**.  
[PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
- Lutz BJ, Ellen Young M, Cox KJ, et al.: **The crisis of stroke: experiences of patients and their family caregivers.** *Top Stroke Rehabil.* 2011; **18**: 786–797.  
[PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
- Lutz BJ, Young ME, Creasy KR, et al.: **Improving stroke caregiver readiness for transition from inpatient rehabilitation to home.** *Gerontologist.* 2017; **57**: 880–889.  
[PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
- Moon M: **The unprepared caregiver.** *Gerontologist.* 2017; **57**: 26–31.  
[PubMed Abstract](#) | [Publisher Full Text](#)
- Caplan LR: *Caplan's stroke.* Cambridge University Press; 2016.
- Zhao F-Y, Yue Y-Y, Li L, et al.: **Clinical practice guidelines for post-stroke depression in China.** *Braz J Psychiatry.* 2018; **40**: 325–334.  
[PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
- Turcotte M: **Family caregiving: What are the consequences?** In: *Statistics Canada.* (ed.). Canada: Minister of Industry; 2013.
- Dharma KK, Damhudi D, Yarden N, et al.: **Increase in the functional capacity and quality of life among stroke patients by family caregiver empowerment program based on adaptation model.** *Int J Nurs Sci.* 2018; **5**: 357–364.  
[PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
- Liu C, Marino V, Sheehan OC, et al.: **Association between caregiver engagement and patient-reported healthcare**

- utilization after stroke: a mixed-methods study.** *Top Stroke Rehabil.* 2020; **27**: 1–7.  
[PubMed Abstract](#) | [Publisher Full Text](#)
23. Rahman R, Dewi FST, Setyopranoto I: **Dukungan keluarga dan kualitas hidup penderita stroke pada fase pasca akut di Wonogiri.** *Berita Kedokteran Masyarakat.* 2017; **33**: 383–390.  
[Publisher Full Text](#)
24. Johnson W, Onuma O, Owolabi M, *et al.*: **Stroke: a global response is needed.** *Bull World Health Organ.* 2016; **94**: 634.  
[PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
25. Kruithof WJ, Post MW, van Mierlo ML, *et al.*: **Caregiver burden and emotional problems in partners of stroke patients at two months and one year post-stroke: Determinants and prediction.** *Patient Educ Couns.* 2016; **99**: 1632–1640.  
[PubMed Abstract](#) | [Publisher Full Text](#)
26. Hu P, Yang Q, Kong L, *et al.*: **Relationship between the anxiety/depression and care burden of the major caregiver of stroke patients.** *Medicine.* 2018; **97**.  
[PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
27. Oliva-Moreno J, Peña-Longobardo LM, Mar J, *et al.*: **Determinants of informal care, burden, and risk of burnout in caregivers of stroke survivors: the CONOCES study.** *Stroke.* 2018; **49**: 140–146.  
[PubMed Abstract](#) | [Publisher Full Text](#)
28. Yang JO, Lee HK: **Factors influencing burnout in primary family caregivers of hospital-based home care patients.** *J Korean Acad Community Health Nurs.* 2018; **29**: 54–64.  
[Publisher Full Text](#)
29. Ferro JM, Santos AC: **Emotions after stroke: A narrative update.** *Int J Stroke.* 2020; **15**: 256–267.  
[PubMed Abstract](#) | [Publisher Full Text](#)
30. Irawanto D: **An Analysis Of National Culture And Leadership Practices In Indonesia.** *J Divers Manag.* 2009; **4**: 41–48.  
[Publisher Full Text](#)
31. Paryono W, Hendrawan DA, Satiti S, *et al.*: **Roles and problems of stroke caregivers: A qualitative study in Yogyakarta, Indonesia (Version dataset) [Data set].** *Zenodo.* 2021.  
[Publisher Full Text](#)

# Open Peer Review

Current Peer Review Status:  

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## Version 2

Reviewer Report 07 February 2022

<https://doi.org/10.5256/f1000research.120742.r121718>

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**Thuan Duc Nguyen** 

Department of Neurology, Military Hospital 103, Vietnam Military Medical University, Hanoi, Vietnam

I do not have any further comments to make.

**Competing Interests:** No competing interests were disclosed.

**Reviewer Expertise:** Stroke, Clinical Neurology especially Pain, Movement disorders.

**I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.**

Reviewer Report 03 February 2022

<https://doi.org/10.5256/f1000research.120742.r121717>

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**Aznida Firzah Abdul Aziz** 

Department of Family Medicine, Faculty of Medicine, Universiti Kebangsaan Malaysia Medical Centre, Kuala Lumpur, Malaysia

The authors have revised the manuscript well- and the results and discussion of themes are better organised.

Note:

The quantitative results can be improved i.e.,

- "...median age of 36 years (interquartile range [IQR] was 17)" can be written as "...median age of 36 (IQR 17) years."
- "Patients' median age was 72 years (IQR was 14)" can be written as "Patients' median age was 72 (IQR 14) years"

The Conclusion section usually answers the study objectives, i.e., for this study refers to "...aims to explore the roles and problems of post-stroke caregivers in Indonesia". Hence the conclusion should recommend that future studies address the problems identified in this study and how to overcome them. Example would be perhaps to explore a module designed for training professional caregivers - since the problems highlighted in the study were mainly salaried caregivers. And the module would be appropriately written to address the educational level of the caregivers - instructions in lay person language, how to communicate with patients' relatives, addressing stress issues in caregivers e.g. to consider respite care for caregivers such as days or hours off from caregiving.

**Competing Interests:** No competing interests were disclosed.

**Reviewer Expertise:** Family Medicine, Health system Research, Community Stroke & Economic evaluations

**I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.**

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### Version 1

Reviewer Report 29 October 2021

<https://doi.org/10.5256/f1000research.55371.r94920>

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**Thuan Duc Nguyen**

Department of Neurology, Military Hospital 103, Vietnam Military Medical University, Hanoi, Vietnam

Stroke is the leading cause of disability worldwide and has become a socioeconomic burden for our society. Caring for stroke survivors can play a crucial role in their continuous recovery in which caregiver is indispensable to these activities. The study mentioned roles and problems of post-stroke caregivers, which is meaningful in clinical practice. The manuscript is well-written, presents the research contents in detail as well as analyzes, synthesizes and draws out results consistent with the research objectives. However, there are a few points the authors also need to pay attention to:

1. Data collection needs to be very accurate and avoid interference because the data here are

completely subjective information of the research object. For example, participant 6 said " ...yes, I stand by for 24 hours. At night I sometimes sleep next to him, to supervise him..." - Is it really accurate to be with the patient 24 hours a day? When will the caregiver sleep?

2. The study sample size is too small to draw general representative results. A very important problem related to caregiver is the lack of sympathy, sharing and love for the patients. They take care of patients after stroke often for the sake of salary and purely for responsibility. Is this problem encountered in this study?
3. Of the caregiver's roles and problems, which one is the most important? Can the authors rank the importance of those roles and issues?
4. The research objective only mentions the roles and problems of caregivers, so the conclusion should only focus on this point, not giving the opinion "*Understanding the roles and problems of caregivers may help facilitate better management and increase the quality of life for both patients and their caregiver*". The author can suggest and suggest some points for further research in the future, which is more reasonable.

I hope the authors can edit, supplement and add their own discussion to make the study even more complete. This is really an interesting study.

**Is the work clearly and accurately presented and does it cite the current literature?**

Yes

**Is the study design appropriate and is the work technically sound?**

Yes

**Are sufficient details of methods and analysis provided to allow replication by others?**

Yes

**If applicable, is the statistical analysis and its interpretation appropriate?**

Yes

**Are all the source data underlying the results available to ensure full reproducibility?**

Yes

**Are the conclusions drawn adequately supported by the results?**

Partly

**Competing Interests:** No competing interests were disclosed.

**Reviewer Expertise:** Stroke, Clinical Neurology especially Pain, Movement disorders.

**I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard, however I have significant reservations, as outlined above.**

Author Response 27 Jan 2022

**Amelia Nur Vidyanti**, Faculty of Medicine, Public Health, and Nursing, Universitas Gadjah Mada, Yogyakarta, Indonesia

**Title: Roles and Problems of Stroke Caregivers: A Qualitative Study in Yogyakarta, Indonesia.**

**Response to reviewer 2**

*We wish to thank you all for your constructive comments in this review. Your comments provided valuable insights to refine its contents.*

**Comments**

Stroke is the leading cause of disability worldwide and has become a socioeconomic burden for our society. Caring for stroke survivors can play a crucial role in their continuous recovery in which caregiver is indispensable to these activities. The study mentioned roles and problems of post-stroke caregivers, which is meaningful in clinical practice. The manuscript is well-written, presents the research contents in detail as well as analyzes, synthesizes and draws out results consistent with the research objectives. However, there are a few points the authors also need to pay attention to:

- Data collection needs to be very accurate and avoid interference because the data here are completely subjective information of the research object. For example, participant 6 said "...yes, I stand by for 24 hours. At night I sometimes sleep next to him, to supervise him..." - Is it really accurate to be with the patient 24 hours a day? When will the caregiver sleep?

**Response:** Thank you for your question. To clarify this quote, this statement from the participant was to depict that her duty was to standby for 24 hours. Of course, she did not wake up all day for 24 hours for monitoring and helping her patient. However, she meant that she was standby to caring her patient.

- The study sample size is too small to draw general representative results. A very important problem related to caregiver is the lack of sympathy, sharing and love for the patients. They take care of patients after stroke often for the sake of salary and purely for responsibility. Is this problem encountered in this study?

**Response:** The caregivers' problem we found in the present study is not lack of sympathy, sharing and love for the patient, but more to lack of respect between caregivers and (other) family members. The different findings may be due to different definitions of caregivers in Asian population. We mentioned this in the revised version in line 64-72. In Asian population, the responsibility of caring the post-stroke patients mostly relies on family members, particularly the spouse or offspring who can provide caregiving in home-bound setting.

- Of the caregiver's roles and problems, which one is the most important? Can the authors rank the importance of those roles and issues?

**Response:** Thank you for your question, but we're afraid that we cannot rank these roles and problems as we did not collect any quantitative data about these issues. We aim to identify the roles and problems of caregiving qualitatively.

- The research objective only mentions the roles and problems of caregivers, so the conclusion should only focus on this point, not giving the opinion "*Understanding the*

*roles and problems of caregivers may help facilitate better management and increase the quality of life for both patients and their caregiver".* The author can suggest and suggest some points for further research in the future, which is more reasonable.

**Response:** We would like to refine our conclusions. We agree that by understanding roles and problems of caregiver does not automatically improve post-acute care of stroke patient. Here is the revised conclusion:

### Conclusions

Caregivers play an essential role in connecting patients with medical personnel and other family members, as well as maintaining the patient's physical and psychological condition. Meanwhile, the problems faced by caregivers face the problems of were lack of support from patients' family, lack of knowledge, suboptimal service, lack of communication and caregivers' burnout. Further research to study the effects of these findings on the quality of life of both patient and their caregiver, as well as how to handle the caregiver issues should be investigated.[hd1]

[hd1] [hd1] Revised conclusion as reviewer 2 suggested.

**Competing Interests:** No competing interests were disclosed.

Reviewer Report 05 October 2021

<https://doi.org/10.5256/f1000research.55371.r94919>

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**Aznida Firzah Abdul Aziz**

Department of Family Medicine, Faculty of Medicine, Universiti Kebangsaan Malaysia Medical Centre, Kuala Lumpur, Malaysia

**Title: Roles and Problems of Stroke caregivers: A Qualitative Study in Yogyakarta, Indonesia.**

### Abstract:

Satisfactory.

### General impression:

This is a novel attempt to document the roles and problems of stroke caregivers in Indonesia. The methodology is sound, but the manuscript would benefit from a more detailed description and discussion of the subject matter. The study setting needs to be introduced in greater detail as caregivers' roles are very much affected by healthcare system differences across the world. Post stroke care is very challenging particularly for the LMIC, and especially for countries in the ASEAN region. Caregiver definitions in the Asian perspective also differ from western literature - and this should be highlighted in the write up. The authors may refer to this article (which I was involved

with) by Ozdalifah O *et al.* (2021) <sup>1</sup> for definitions of stroke caregivers.

Overall, this manuscript has potential to be accepted after major revision/refinement.

**Introduction:**

This section was too brief (2 paragraphs) and did not highlight the caregiver situation in Indonesia (i.e. what is the norm in post stroke care, and who constitutes as caregiver?). There is mention that caregivers are made up of family members and professional caregivers. Suggest to highlight and define what professional caregivers are (i.e. salaried professional nurse/ therapist/trained domestic helper etc.) and where were the caregivers located - is it in the patients' own home or at a inpatient rehabilitation facility/ nursing home?

**Method:**

Focus group discussion was conducted to explore the roles and problems of caregiving (only ONE FGD was conducted, as mentioned in the article).

**Sample recruitment:**

"Inclusion criteria were: (1) family or professional caregivers, who caregiving a post-stroke patient with any level of disability; and (2) providing care for  $\geq 1$  year."

**Comment:**

The definition of professional caregivers is unclear. Do you mean professional caregivers as trained and/or were they salaried caregivers?

**Data analysis:**

Why was the transcription not distributed to the caregivers for checking, verification? Is there a specific reason for this?

**Results:**

All subjects (caregivers) were female, median age of 36 years (?IQR), patients' median age was 72 years (?IQR).

**Discussion:**

**Roles of caregiver: Communication:**

The areas where communication problems most likely to occur should be grouped, summarized and examples quoted accordingly. Suggest to include examples of communication between:

- Caregiver and patient;
- Caregiver and medical personnel i.e. doctor;
- Therapists and doctor.

**Role of caregiver: maintain patients' health:**

Similarly, the flow of this section can be improved by citing the quotes after each point. Please maintain a consistent format throughout the results section. Below are suggested rewrites:

Paragraph 2:

- "For providing basic need fulfilment, caregivers help patients with disabilities in need of self-care and mobility such as feed, bathing, showering, toileting, dressing, grooming, walking and transferring..."



- “Caregivers also monitor the sleep pattern of their patients and help them to have good and adequate sleep.”
- “...yes, I standby for 24 hours. At night I sometimes sleep next to him, to supervise him...”(participant 6, ?family/professional caregiver)

Paragraph 3.

- “During rehabilitation, caregivers play a role in assisting rehabilitation processes by giving additional physiotherapy services at home. This is in accordance with the rehabilitation recommendations that families and caregivers are involved in determining the goals and implementation of post-stroke rehabilitation.<sup>8</sup>”
- “..besides visiting physiotherapists in a hospital or inviting them to do home care services, in the morning and afternoon we usually have short additional physiotherapy session, only several minutes, just to stretch some muscles...” (participant 17, family / professional caregiver).
- Caregivers’ problems: unappreciated and unconcerned family.
- “Moreover, the family did not give enough appreciation to the caregivers.
- “no respect from the family” (participant 2, ?professional/family caregiver)

### **Conclusion:**

This section should summarise and provide recommendations on how to handle the caregiver issues. E.g. identifying relevant information which should be passed on to the identified caregiver: information regarding stroke; overall management/rehabilitation plans; communication strategies between caregiver-therapist-doctor; therapist-caregiver; professional caregiver-family; caregiver respite issues (teaching caregivers on how to handle or cope with burnout, for professional caregivers to be given scheduled respite hours/days).

### **References**

1. Omar O, Abdul Aziz A, Ali M, Ali Ja S, et al.: Caregiver Depression Among Home-Bound Stroke Patients in an Urban Community. *Cureus*. 2021. [Publisher Full Text](#)

**Is the work clearly and accurately presented and does it cite the current literature?**

Yes

**Is the study design appropriate and is the work technically sound?**

Partly

**Are sufficient details of methods and analysis provided to allow replication by others?**

Yes

**If applicable, is the statistical analysis and its interpretation appropriate?**

Not applicable

**Are all the source data underlying the results available to ensure full reproducibility?**

Yes

**Are the conclusions drawn adequately supported by the results?**

Partly

**Competing Interests:** No competing interests were disclosed.**Reviewer Expertise:** Family Medicine, Health system Research, Community Stroke & Economic evaluations**I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard, however I have significant reservations, as outlined above.**

Author Response 27 Jan 2022

**Amelia Nur Vidyanti**, Faculty of Medicine, Public Health, and Nursing, Universitas Gadjah Mada, Yogyakarta, Indonesia**Title: Roles and Problems of Stroke Caregivers: A Qualitative Study in Yogyakarta, Indonesia.****Response to reviewer 1.**

We wish to thank you all for your constructive comments in this review. Your comments provided valuable insights to refine its contents. Because one of the objectives of this study is to widen our knowledge about caregivers' roles and problems, especially in Indonesia, we would like to refine our paper. As you advise us to, more detail about this study setting and definitions about caregivers which enrolled in this study have been added.

**Comment 1****Introduction:**

This section was too brief (2 paragraphs) and did not highlight the caregiver situation in Indonesia (i.e. what is the norm in post stroke care, and who constitutes as caregiver?). There is mention that caregivers are made up of family members and professional caregivers. Suggest to highlight and define what professional caregivers are (i.e. salaried professional nurse/ therapist/trained domestic helper etc.) and where were the caregivers located - is it in the patients' own home or at a inpatient rehabilitation facility/ nursing home?

**Response:** We would like to thank you all for this comment. We agree that the differences in who cares for stroke patients (nurse or nonmedical-trained person) should be included in introduction to give our readers a bit of knowledge about how stroke patients are being cared in Indonesia. We have also added a reference as you suggest in refer to the definition of caregivers in Asian population.

**Revised text :**

Caregivers can be either formal or informal caregivers<sup>6</sup>. Formal care is delivered by professionals, such as nurses, physiotherapists, or speech and occupational therapists.

Informal caregivers can be paid or unpaid. Unpaid informal caregivers are family members, friends, or relatives, meanwhile paid informal ones are domestic helpers or trained individuals<sup>6</sup>. Caregiving services can be provided in a home-based setting, a rehabilitation facility, or a nursing home<sup>7</sup>. In Asian population, the responsibility of caring the patients mostly relies on family members, particularly the spouse or offspring who can provide caregiving in home-bound setting<sup>8</sup>. [ANV1]

#### Comment 2

##### **Method:**

Focus group discussion was conducted to explore the roles and problems of caregiving (only ONE FGD was conducted, as mentioned in the article).

##### **Sample recruitment:**

"Inclusion criteria were: (1) family or professional caregivers, who caregiving a post-stroke patient with any level of disability; and (2) providing care for  $\geq 1$  year."

##### **Comment:**

The definition of professional caregivers is unclear. Do you mean professional caregivers as trained and/or were they salaried caregivers?

**Response:** We thank for your valuable comment. In this study, we recruited only informal caregivers. We apologize by making a mistake in mentioning professional caregivers. Hence, we have revised the text as below:

Inclusion criteria were: (1) family caregivers or a domestic helper[hd2] ,.

#### Comment 3

##### **Data analysis:**

Why was the transcription not distributed to the caregivers for checking, verification? Is there a specific reason for this?

**Response:** There was no specific reason for not returning the transcript to respondents. We realize that it may lead to bias or misinterpretation, thus we put this issue in the limitation. We will take this point as a suggestion for improvement in further research.

#### Comment 4

##### **Results:**

All subjects (caregivers) were female, median age of 36 years (?IQR), patients' median age was 72 years (?IQR).

**Response:** Initially we only used median, minimum, and maximum number due to the sample size for this study is small. However, we have added the interquartile range as well in the revised version as below:

We enrolled seven caregivers; all subjects were female with a median age of 36 years (interquartile range [IQR] was 17)[ANV3] . All had home-based responsibilities and half of them had less than 5 years of caregiving experience. These caregivers managed five post-acute stroke patients. Patients' median age was 72 years (IQR was 14)[ANV4] . Four (57.2%) of the caregivers had higher education while the other three (42.8%) had secondary

education.

#### Comment 5

##### **Discussion:**

##### **Roles of caregiver: Communication:**

The areas where communication problems most likely to occur should be grouped, summarized and examples quoted accordingly. Suggest to include examples of communication between:

- Caregiver and patient;
- Caregiver and medical personnel i.e. doctor;
- Therapists and doctor.

**Response:** Communication problems had been found in caregivers' problems' section. We have rewritten this section as you suggest us to. Communication problems between therapists and doctors, while were very likely to occur, were not surfaced during FGD. There were some other themes that likely been caused by this particular problem (therapists and doctor's communication), however we're afraid that were just our assumption so we did not include this in our writing.

Despite of this, we have re-organized the communication problems and added one more quote to describe related to communication problem between caregivers and the patients:

##### **Caregivers' problems: lack of communication**

Perceptions that were obtained from the caregivers were that there was a lack of communication between medical personnel causing uncollaborative patient management. They stated that this caused the patient's treatment was to be time-consuming. Poor communication is associated with less effective services<sup>7</sup>.

The problems above can be seen in the following quote:

*"...for example, the physiotherapist came and asked about the patient's development, then I explained 'Oh she is blah, blah, blah', 'Okay, I will report it to the doctor'. Later, the doctor will come empty-handed...seems like uninformed. That is what sometimes makes us disappointed..."*(participant 7) [hd5]

Apart from communication problems with medical personnel, we also found that communication problems with patients became a burden for the caregiver. This is especially experienced with patients who have communication disorders. In long-term care setting, caregivers' anxiety rates have decreased. Nonetheless, caregivers' depression rates and burdens are still high<sup>25</sup>.

This was an example which expressing this problem:

*"... after her second stroke she really was deteriorated, we didn't know whether she still recognized us or not because there were no response at all from her, she was only staring but it's a blank stare..."*[hd6]

#### Comment 6

##### **Role of caregiver: maintain patients' health:**

Similarly, the flow of this section can be improved by citing the quotes after each point. Please maintain a consistent format throughout the results section. Below are suggested rewrites:

Paragraph 2:

- "For providing basic need fulfilment, caregivers help patients with disabilities in need of self-care and mobility such as feed, bathing, showering, toileting, dressing, grooming, walking and transferring..."
- "Caregivers also monitor the sleep pattern of their patients and help them to have good and adequate sleep."
- "...yes, I standby for 24 hours. At night I sometimes sleep next to him, to supervise him..."(participant 6, ?family/professional caregiver)

Paragraph 3.

- "During rehabilitation, caregivers play a role in assisting rehabilitation processes by giving additional physiotherapy services at home. This is in accordance with the rehabilitation recommendations that families and caregivers are involved in determining the goals and implementation of post-stroke rehabilitation.<sup>8</sup>"
- "...besides visiting physiotherapists in a hospital or inviting them to do home care services, in the morning and afternoon we usually have short additional physiotherapy session, only several minutes, just to stretch some muscles..." (participant 17, family / professional caregiver).

**Response:** We have re-organized this section by citing the quote after each point in order to improve the flow of writing.

### **Roles of caregiver: maintaining patients' health**

Caregivers as the person people who daily assist patients' activities, hold responsibility for patients' health care. Caregivers provide basic needs fulfillment, and rehabilitation processes, as well as prevention and management of complications<sup>7,11</sup>.

For providing basic need fulfillment, caregivers help patients with disabilities in need of self-care and mobility such as feeding, bathing or showering, toileting, dressing, grooming, walking, and transferring.

This quote below is an example from participant about this role:

*"...within a day, our services are bathing, when it is eating time we feed them, and.. usually Mr M is simple, after bathing we feed him via PEG..."* (participant 4)[hd7]

Caregivers[ANV8] also monitor the sleep pattern of their patients and help them to have good and adequate sleep<sup>11,12</sup>.

We can see this role in this quote:

*"...yes, I stand by for 24 hours. At night I sometimes sleep next to him, to supervise him..."* (participant 6)[hd9]

During rehabilitation, caregivers also play a role in assisting rehabilitation processes by giving additional physiotherapy services at home. This is in accordance with the rehabilitation recommendations which stated that families and caregivers are involved in determining the goals and implementation of post-stroke patient rehabilitation<sup>10</sup>.

Role of caregiver in helping rehabilitation can be seen in this quote:

*"...besides visiting physiotherapists in a hospital or inviting them to do home care services, in the*

*morning and afternoon we usually have short additional physiotherapy session, only several minutes, just to stretch some muscles..." (participant 1)[hd10]*

Furthermore, caregivers plays essential roles to in preventing and managing complications that eventually may eventually develop. This role is in accordance with a previous study which found that caregivers can help reduce the incidence of post-stroke complications<sup>13</sup>. However, the study above used a formal training program for caregivers which was rather too impractical to be implemented in this study. The importance of training or and education for caregivers is also supported by other studies that showed a reduction in complications through providing education programs to caregivers<sup>14</sup>.

This[ANV11] role can be seen in the following quote:

*"...because my mother is ee .. her mobility is very limited, thus I need to feeding her using feeding tube. Other than that, what is it called? Catheter? Yes, a catheter! My mother is prone to urinary tract infection due to the catheter. Hence, sometimes if this infection develops, I have to... really have to do this, um ... to keep it clean..."(participant 7)*

Based on the above discussion, it can be observed that maintaining a the good health of post-stroke patients is the responsibility of the caregiver. This is in accordance with prior studies which stated that there are major changes in the responsibilities of families caring for post-acute stroke patients<sup>15-17</sup>.

This can be elaborated with the quote from one of the interviewees below:

*"... this is my responsibility that she is completely dependent on us ... so we take care of her like 'because she is already completely dependent on us, so whatever happens to her, in my mind, it counts on us'..."(participant 6)*

#### Comment 7

- Caregivers' problems: unappreciated and unconcerned family.
- "Moreover, the family did not give enough appreciation to the caregivers.
- "no respect from the family" (participant 2, ?professional/family caregiver)

**Response:** We appreciate reviewer's comment related this matter. Caregivers' problems related to unappreciated and unconcerned family were the problems faced by domestic helpers as the informal caregivers. Therefore, we have written additional explanation in the quotes of participant 2 and 3, as written in the revised text.

During the discussion, it was found that the family was not prepared for an emergency situation. This can delay early patient management. Meanwhile, some interviewees, domestic helpers being as informal caregivers[ANV12], did not dare to take action before instruction had been given or a decision was made by the family, even though the patient was in an emergency condition. This occurred because the caregiver was afraid of being blamed, which can be seen in the following statement:

*"...we are afraid that later we will be blamed. I've experienced that. It's like 'that's to bold', or in Javanese 'kok wani-wanine (how dare you?); even though we already did our best..."(participant 3, a domestic helper[ANV13])*

Another caregiver said that she had been scolded when she encountered similar situation, like in the phrase below:

"*Even got scolded*" (participant 3, a domestic helper[ANV14])

Moreover, the family did not give enough appreciation to the caregivers.

"*no respect from the family*" (participant 2, a domestic helper[ANV15])

#### Comment 8

##### **Conclusion:**

This section should summarize and provide recommendations on how to handle the caregiver issues. E.g. identifying relevant information which should be passed on to the identified caregiver: information regarding stroke; overall management/rehabilitation plans; communication strategies between caregiver-therapist-doctor; therapist-caregiver; professional caregiver-family; caregiver respite issues (teaching caregivers on how to handle or cope with burnout, for professional caregivers to be given scheduled respite hours/days).

**Response:** We appreciate your suggestions. However, we're afraid that providing recommendation to handle these issues is out of scope of this paper. Maybe we can add some opinion to add some solution to these issues, but as the aim of this paper is to widen and deepen our knowledge about roles and problems of caregivers', we decided not to add recommendation on how to handle the caregiver issues. Nevertheless, we have added a closing statement in the conclusion as below:

Further research to study the effects of these findings on the quality of life of both patient and their caregiver, as well as how to handle the caregiver issues should be investigated.[hd16]

[ANV1] As reviewer 1 suggested, we add more explanation about caregivers and the setting/location of care provided

[hd2] As reviewer 1 asked, we clarify the type of caregivers recruited

[ANV3] As reviewer 1 suggested, we add the IQR

[ANV4] As reviewer 1 suggested, we add the IQR

[hd5] The quote has been organized and moved right after the first paragraph

[hd6] As reviewer 1 suggested, we add one more quote related to communication problem between caregivers and the patients

[hd7] We add one more quote to provide more example related to the role of caregivers for providing basic needs

[ANV8] As reviewer 1 suggested, we have moved citing the quote after each point to improve the flow of writing

[hd9] As reviewer 1 suggested, we have moved citing the quote after each point to improve the flow of writing

[hd10] As reviewer 1 suggested, we have moved citing the quote after each point to improve the flow of writing

[ANV11] As reviewer 1 suggested, we have moved citing the quote after each point to improve the flow of writing

[ANV12] Additional explanation related to the status of caregivers as domestic helpers

[ANV13] Additional explanation related to the status of caregivers as domestic helpers

[ANV14] Additional explanation related to the status of caregivers as domestic helpers

[ANV15] Additional explanation related to the status of caregivers as domestic helpers

[hd16] Usulan revisi kesimpulan sesuai dengan saran reviewer 2

**Competing Interests:** No competing interests were disclosed.

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