

ORIGINAL ARTICLE

“I feel hard...”: An exploration of physical health experience among caregivers in providing care of stroke-survivors.

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Abstract:

As the prevalence of stroke survivors is increasing each year, the demands among caregivers are also increasing where the stroke patients tend to rely on the help of caregivers to fulfil their daily needs. The increasing demands from the stroke survivors cause the caregivers at high risk of having the physical effects of caregiving. The study aims to explore the caregivers' experience in taking care of stroke survivors who live in rural areas. This is a phenomenological study on three caregivers of stroke survivors living in a rural area located in Sabah. By using Interpretative Phenomenological Analysis (IPA), a theme emerged which is “*I feel hard ...*” in relation to body pain, muscle soreness, reduce in physical performance and fatigue. It can be concluded that there are negative physical effects of taking care of stroke survivors among caregivers living in rural areas.

Keywords: Caregivers, exploration, physical effects, stroke

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1. INTRODUCTION

Stroke is globally reported to be the second leading cause of death and the third leading cause of disability [10]. Stroke is defined as progressing neurological dysfunction due to the disturbance in the blood flow to the cerebral causing brain cell death [10]. In the United Kingdom, each year, there are more than 100, 000 cases reported that it is estimated about one stroke case for every five minutes [17]. It is found that the rate of stroke, who experience stroke for the first time, aged 45 and above is expected to increase by 59% during the year 2035, and it is undeniable that the adding numbers of stroke people will make the total of stroke survivor figures to rise by 123% [17]. In Malaysia, stroke is the third leading cause of death after ischemic heart disease and pneumonia [6]. The prevalence of ischemic and hemorrhagic stroke is raised by 29.5% and 18.7%, respectively each year [2].

Due to physical and psychological dysfunctions, those who are affected by any chronic illness, including stroke, are most commonly to suffer from the disturbance in their daily functioning and limitation in the ability to look after themselves [21]. With these limitations, they require constant and prolong support and assistance from their family members in fulfilling their basic needs. An interruption in the family members' regular routines such as social participation and leisure activities, cause the family members to stress that interfere with their personal life. A study has highlighted that stroke survivors who are being taken care in the nursing home has a better prognosis with a

lower mortality rate and died significantly later than those who were discharged directly to their home [11]. This show that caregivers with formal, well-trained and prepared with proper knowledge in handling stroke patients provide with better care. Being a caregivers to a person with stroke is a crucial role in giving them support in the process of them transitioning from the health care system into the community [8].

Informal caregivers, mostly among spouses or daughters, are the people who provide care without any preparation training into caring for disabled people, while formal caregivers such as rehabilitation nurses are those who have some degree of training into caring for the people with disability [13]. The previous study has found that caregivers, particularly the informal one, play a significant role in caring for stroke survivors [8]. The immediate effect of the stroke needs the caregivers to give consistent support as the early stroke continuously tends to be dependent on the caregivers' help. A recent study has found that activities involving caregiving are closely associated with low-back pain development [18]. The progressing severity of low back pain causes difficulty in performing activities of daily living, especially those activities that involve bending and extending the lower back. Poor body positioning and activities that include prolonging static position have been identified as the major contributing factors for the progressing low back pain among caregivers, specifically those who taking care of stroke survivors [18]. A study has listed that the effects that most commonly faced by the caretakers are multidimensional, which include physical,

social, psychological and financial [3]. However, this study is only focusing on the physical effects of providing care to stroke survivors.

As the prevalence of stroke survivors is increasing, especially in the Malaysian context, most of the stroke survivors depend on caregivers to provide them with daily needs and care [13]. The increasing environmental demands that exceed the level of compliance of a caregiver much more or less will affect the caregivers, either physical and psychological functions [19]. A study has found the development of low back pain are closely associated with those who are bound to provide care for the disables [18]. The pain at the lower back tends to be progressing becoming more severe, leading to struggle in doing daily living activities, mainly repeated extending and bending movement of the lower back. A study has indicated that the informal caregivers, in particular, who have little knowledge regarding the caretaking task of a stroke patient may develop or have progressing low back pain due to the prolong static and poor body position during caring as this is the major contributor of back pain [18].

This research aimed to explore the experience in providing care to stroke survivors living in rural areas. The purpose of this study was to explore the physical effect of caregivers upon providing cares for stroke survivors living in rural areas. By conducting this research, it would provide better awareness and insights into the physical effect of caring for the stroke-survivors on the caregivers to the health care professionals, especially among the occupational therapy professions. Thus, occupational therapy may collaborate with other professions such as physicians, nurses and community workers, and plan for future implementation of intervention programs for the caregivers of stroke survivors and providing support in helping to reduce the adverse negative impact of caregiving.

2. MATERIALS AND METHOD

2.1. Study design

This was a qualitative study which employs a phenomenological design to describe the real-life experience of a phenomenon [16]. A semi-structured interviews were selected as the most appropriate technique in collecting the data since it offer a greater data collection as it goes into details of the complexity of the informal caregivers' daily experience in caring for the stroke survivors as well as helping in ensuring better rapport between the interviewer and the respondents which may assist in discussing a more sensitive topic in stroke caregiving [13].

2.2. Study setting

The study was conducted between August 2018 and April 2019 in Kampung Benoni, Papar located in a rural area in Sabah. Sabah was chosen as the primary setting for data collection as it had been recorded to be the highest incidence of poverty in the year of 2012 and thus, had made it as one of the most top rural areas in Malaysia [6].

2.3. Respondents and recruitment

A total of 5 targeted primary caregivers interviewed regarding the stroke caring duty. Recruited as the respondents of the study, one must fit the following inclusive criteria:

- i. The caregiver must be aged 18 years old and above.
- ii. The caregiver is a primary informal caregiver to the stroke survivor.
- iii. The caregiver must score more than 25 that indicates to have a good cognitive function from the Malay version of Mini Mental State Examination (M-MMSE) test [24].
- iv. Malay version of Depression, Anxiety, Stress Scale (DASS-21) [12] assessment shows a score of 0-9 that indicate normal mental health.
- v. Modified Barthel Index (MBI) assessment [15] shows a score of 0-74 that indicate moderate to total dependency level of the stroke survivors on the primary caregiver.
- vi. The caregiver must be able to understand and respond to questions.

The study has achieved a saturation level of research at three respondents. The saturation level of the data collected was achieved when there was no addition of new information and further coding cannot be done [7].

2.4. Data collection

The researcher has designed a semi-structured interview guideline adapted from [13] which combines open-ended structured questions, to prompt interview session[appendix A]. Each respondent also answered three screening assessments, which were DASS-21 M malay version, M-MMSE and MBI, before proceeding into the interview session. An audio recorder was used to record the responses and avoid missing of data. Each interview session lasted approximately 45 to 60 minutes. Interview session performed at the caregivers' home.

2.5. Data analysis

Each of the caregiver's responses was transcribed into transcribed verbatim. The data collected was then analysed by using the Interpretative Phenomenological Analysis (IPA) that is a qualitative approach to provide more detail examination of personal lived experience [16]. The information collected in the interviews by using an interview guide and following the detailed IPA analysis, a superordinate emerged in the relation of four subordinate themes [Table 1.]

2.6. Trustworthiness

The research has designed an interview guideline that was adapted from the previous study [13] and validated by peer debriefing. This study also adopted a well-established method of analysing the data, which is IPA to enhance the trustworthiness of the study. The emergent themes have gone through multiple peer debriefing session to receive feedback regarding the results. Also, member checking on the

developed themes was performed to clarify the validity of the data [4].

2.7. Ethical consideration

The study was approved by the Research Committee of University Teknologi MARA (UiTM). All respondents were provided with written, informed consent before the beginning of the interview.

3. RESULT AND DISCUSSION

3.1. Finding

From the finding of the study, it was revealed that there is one superordinate theme emerged which is "I feel hard ...", in relation with four subordinate themes which are body pain, muscle soreness, reduce in physical performance and fatigue. Refer Table 1 for a summary of the results.

Table 1. Identified Themes Of The Results

Superordinate theme	Subordinate themes
"I feel hard..."	<ul style="list-style-type: none"> • Body pain • Muscle soreness • Reduce physical performance • Fatigue

All caregivers stated that they had suffered physically as a consequence of the stroke's caring. This effect was announced to be at its peak immediately after the occurrence of a stroke on their family members and during the first few months of adjusting to the changes of dependency on the caregivers. Most of the caregivers complained to bear the burden of physical pain as an aftermath. They claimed that the routine of caring stroke patients has led to low back pain. The frequent and repeated movement in which they need to help the disable relatives to position themselves makes it hard for the caregivers as they need to do it every day to ensure the patients' to be comfortable. This can be observed in the excerpt below;

"The hardest part of being a caregiver is when I need to clean mother after she has finished excreting. I need to lift and push her frequently to clean her. After I cleaned her, I could feel my lower back in pain. I need to take a rest before I do other things. [Mrs. R]."

On the other hand, an increase in the burden of caring also contribute to the pain at the lower back that the caregivers endure throughout their journey of caretaking, as the following excerpt describe;

"I will try to take care of my father and at the same time not neglecting my responsibility as a wife to take care of my husband who was sick at that time. I need to manage my time to fulfil both needs. After I have done my works with my father, I will continue doing house chores such as cleaning, cooking and doing laundry. I need to rest frequently during the process as the back pain disturbs me from doing my work, making the house chores take longer time to finish. [Mrs. S]."

From the excerpt, the increase in the burden of care significantly conduces to the back pain of caregiving. The carers not only have to take of the stroke survivors. They, who are mostly amongst the female gender, also need to

fulfil their role as a wife, a mother, and a home maintainer. The caregivers need to take care of the stroke survivors and at the same time not neglecting other responsibilities. The increase in burden reported leading to lower back pain among the caregivers.

Another caregiver supported that the increase in burden causes lower back pain. Especially during the first few months after the onset of stroke, the caregiver has not yet used to the routine of caregiving and adapt to the dependency of stroke survivors to the caregiver to fulfil their needs. The caretaker reveals that the first few months is the most difficult phase throughout the whole journey of caring for stroke survivor and is explained in the excerpt below;

"The most challenging phase is during the first one to two months after the mother having a stroke. That time, the mother was still unable to communicate clearly and hard for her to give instruction. Because of that, we have the difficulty to understand what she wanted. Other than that, the mother is unable to move and only lay on the bed. So, we (caregiver and husband) are the one who needs to fully help her to lift her, help her to sit and change her position. [Mrs.M]."

Talking about body pain, a caregiver narrated that she experienced muscle soreness due to the caregiving routine. The routine of caring not only affecting body pain to the provider, but also causing muscle sore. The frequent lifting, pushing and positioning the stroke survivors has led to overuse of the muscle, particularly the muscles of the arms, and lead to discomfort. Poor knowledge of stroke caring causes poor handling of the stroke survivors by the caregivers that will affect the physical health of the caregivers, such as to cause muscle soreness. The caregiver complain;

"I feel limited when doing other activities. For example, when lifting heavy things. It is hard for me to lift heavy things because of muscle sore on my arms. Other than that, cooking and doing house chores also a hard thing to do because of the muscle sore. [Mrs. R]."

The next subtheme arises from the result is a reduction in physical performance. Majority of the caregivers stated that the role of caring stroke survivors had affected them in their daily activities. Their routine has become limited, where they need to take a frequent rest when doing an activity that requires a long process. A caregiver narrated;

"As I said before, this caring duty has affected me in terms of time. I am still able to manage mother, cook for my family and do the house chore. But, I cannot do work continuously. When I clean the house such as sweeping the floor, I cannot continuously sweep. I need to frequently rest, [Mrs. R]."

Another caregiver echoed and supported that caring routine has affected her physical performance. The caregiver mentioned that the most time-consuming and challenging routine is cleaning the stroke survivor after excretion. The routine takes a long process to do and time-consuming, especially when the cleaning process took place on the bed. All the pushing and lifting on bed activities have affected the caregivers' physical performance in which they have to take a rest for a longer time to recover their energy lost before continuing other caring duty.

"I would say cleaning mother after excretion and changing

her bedsheet are the hardest part of being a caregiver. Because I need to move my mother a lot. I have to lift her, push her to the side and position her. It requires a lot of movement. After I have finished it, I have to take a rest. It disturbs me because I have to rest first before doing other work and I cannot do work continuously. [Mrs.M]."

Besides, most caregivers reported to experience fatigue during caring for stroke survivors. The abrupt changes of dependency of stroke survivor have affected the caregivers physically where they have not yet adapted to the caring tasks in the first few months after the onset of stroke causing them to feel fatigued during caretaking task. The frequent lifting and pushing of stroke survivors drained their energy, especially the task of cleaning the stroke survivors. A caregiver said;

"Before this, I have never do activities to lift heavy things. After my mother has a stroke, I have to lift her. That changes are tiring to me. I feel tired because I have never do anything like cleaning an adult after excretion. It is very new to me and I could say that everything is hard. [Mrs. R]."

This is supported by another caregiver who experiences disturbance in sleep because of to fulfil stroke survivor's need leading to fatigue;

"At night, the father will groan due to pain and discomfort when he is laying down. When I heard him groaning, I will immediately wake up and help him to change his position. I help him and support him to sit down for a while. If I am sleepy, I will put him back and go to sleep. After a few minutes, he will groan back because of discomfort. I feel tired of taking care of my father. Even though I am sleepy, I still need to take care of him and his needs. [Mrs. S]."

3.2. Discussion

It is undeniably true that being a primary caregiver to a stroke survivor is a big responsibility and burden to carry. A caregiver has to sacrifice everything and dedicate their time to the maximum to care a person with stroke, especially if the person with stroke is a member of their family. This current study investigates the physical health effects among primary informal caregivers of stroke survivors in a context where they are not trained and prepared with the knowledge of caregiving provided by health services. The analysis of the present study has shown that there are physical effects of stroke caretaking on the caregivers. The findings from this study point up to one superordinate theme, namely "I feel hard..." in relation to the subordinate themes: body pain, muscle soreness, reduce in physical performance and fatigue.

This research provides understanding to a much greater extent on the routine of caring for a stroke survivor. Most of the primary caregivers complained of body pain as one of the most physical impacts of caregiving stroke survivors. They talked about how the routine of caring has given an impact on them physically which is a pain at the lower back. A research conducted to study on the frequency and features of low back pain among the stroke caretakers has found that low back pain is high prevalence in stroke caregivers compared to a healthy population, especially those female caregivers [23]. Similarly, in another research that the common injuries when doing lifting and handling during caretaking activities include back pain, muscular injury,

hernias, knee injuries, and muscular aches [9]. The finding of the current study is agree to the previous research in which caring duty done by the caregivers may cause body pain such as pain at the lower back and muscle soreness particularly during lifting and handling the stroke survivors. This current findings highlighted the theme of body pain that the caregivers experienced due to the caretaking duty as the leading effect of caregiving. It is a result of frequent and repetitive movement that the caregiver did in order to help the person with stroke to position themselves to prevent discomfort. They reported that the routine such as lifting and pushing need to be done every day which lead to pain at the lower back and sore of muscles. Additionally, a study has found a relationship between caretaking activities and poor physical health, leading to a rise in the risk of mortality on caregivers [9]. A comparison between spouse, adult children, and children in law has revealed that caregivers among the spouses are more supportive and less complaining that make them be more exposed to symptoms of depression, and increased in financial and physical burden [1]. As the informal caregivers are usually among the spouses or daughters [13], the government should consider in providing intervention or rehabilitation programs to overcome the problems as the low back pain and muscle soreness issues among the caregivers is a serious matter and it involves the risk of increased mortality in caretakers.

Body pain that the caregivers experienced is also due to the increase in the burden of care. Most of the stroke survivors have to neglect their previous role due to their limitation. The caregivers who are mostly found to be among female eventually have to take over the survivors' previous role. This caused an increase in the burden of the carers as not only they have to take care of their own family, but both the person with stroke and their previous role. A study has found that musculoskeletal injuries such as fatigue, backache, and headache, among the caretakers of chronic physical injuries are associated with the burden of care [5]. Caregivers with a high burden of responsibility are experiencing a greater degree of physical strain due to the demand in taking care of family member with disability[5]. This is because the caregiving tasks may require assistance from the carers to give a substantial to high physical exertion for the stroke survivors causing them to develop back pain in the long run. Not to mention, caregivers also claim that underlying complications such as post-delivery back pain become worse when doing caregiving duty.

Another subtheme that arises from the current research is fatigue and reduce physical performance due to caregiving duty of a stroke survivor. The caregivers of stroke survivors expressed that they need to take over the role of the person with stroke after the onset of stroke. They have to be a multitasker in doing daily routine from caring for their husband and child, to maintain the home and manage the stroke survivors. This leads to adding to the burden in which they need to care not only their husband and child, but also they need to care for the home and manage the stroke patients. Most caregivers complained that the increase in burden cause fatigue and lead to physical exhaustion. Those activities that require high physical demand from the caregivers and time-consuming activities to be specific, the care providers easily have energy depletion subsequently after performing the activities. This causes them to experience a reduction in physical performance where they

reported to have taken frequent rest before proceeding into another duty. A study has pointed out that because of the caretaking responsibilities, the carers are at high risk of experiencing the symptoms and injury of musculoskeletal in which they added fatigue, headache and backache are highly mention manifestation of caring activities in rural areas [5]. They also include physical symptoms among the caretakers are related to a high burden of care [5]. Evidence from preceding research have added caregivers who provide long-lasting nature of care, especially stroke survivors, experienced deterioration in the quality of life and, frustration, fatigue and anger are the most regular expressions [22,14]. This current study has shown that as the burden increase, the caregivers of stroke survivors notably those who are living in a much deprive of services and facilities environment, have a higher probability of being exposed with manifestations and injuries of physical such as fatigue that lead to exhaustion and reduction in physical performance. They also need the concern and support from the government to help in improving life quality.

Talking about fatigue and physical performance, most caregivers also complain of fatigue in doing the caring routine. From the findings, most caretakers indicate that toilet hygiene is the most challenging and difficult part of the routine. As noted in another study [5], toilet hygiene falls the second, after the transfer, of the most frequent daily care routine of stroke survivors that need to be done by carers. There are several possible explanations identified for this result. The complexity of the activity, the frequency of activity need to be performed each day and the duration to finish an activity may give an impact on the physical demand from the caregivers [5]. Toilet hygiene is one of the activities that include multiple tasks along the process. Particularly in those stroke survivors whom dependency level is high, the caregivers need to do dressing and undressing, carrying water and supplies to the bed, cleaning the person with stroke and probably mopping the floor if the activity occurs on the bed. This multi complex activity requires a very high physical demand from the caregivers which will cause fatigue and exhaustion physically. Those stroke survivors with incontinence are not exceptional. Following the fatigue and physically exhausted, their occupations will also be affected as they need to rest and recover which took a long process and time-consuming. These effects cause the care providers to be reduced in physical performance as they need to take a rest for numerous time due to the increase in burden. The present finding is in agreement with the previous study [20], results which showed the incontinence care of person with stroke with immobility, higher level of dependency and requires a full-time care induce the physical impact of caregiving such as fatigue and back pain among the informal caregivers who are lacking in the knowledge of proper caring of stroke survivors.

4. CONCLUSION

When it comes to caregiving, especially to a stroke survivor, it has been known it is not an easy task to do. The abrupt changes of role in providing care for stroke survivors are followed by the adverse and various consequences such as physical effect. To conclude, there are negative physical effects of taking care of stroke survivors. The aftermath of

caring stroke survivors could be prevented from occurring, lessened or control the vast effects from worsened if the care providers were given support, more structured and systematic interventions, and prepped with training and knowledge regarding the role of caregiving stroke survivors.

This paper allows a view of the effect of caregiving stroke survivors living in rural areas that are often neglected in terms of their welfare. It can provide insight and information as the necessary knowledge in constructing and tailoring intervention programs that not only focusing on the stroke patients but also turning the attention toward the person behind in providing care for the stroke survivors. The identified themes suggest avenues of meaningful caregiver support that bear further exploration. It is also vital to enhance the well-being of the caregivers as it much more or less contributes to the health and recovery of the stroke patients.

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Appendix A

1. Would you share with me about yourself?
2. Would you share your experience in taking care stroke survivor?
3. Describe your roles as caregiver for stroke survivor
4. How the responsibility in providing care effect your physical well-being?
5. Any other thing you want to share with me?