

Original article:

Burden of Stroke Caregivers: Evidence from a Qualitative Study in Sarawak, Malaysia

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Abstract

Background: Stroke survivors experience long-term physical, psychosocial and cognitive impairment that are formidable challenges to caregivers because caring for stroke survivors needs explicit knowledge and caregivers have to endure the stressfulness as a result of caring. In addition, little is known about perceived benefits of the stroke care giving experience.

Objectives: This study was aimed to determine the caregivers' burden and challenges as reported by caregivers of stroke survivors. **Materials and Methods:** This was a cross-sectional study involving 18 stroke caregivers. The data were collected from November 2015 to June 2016 at a conveniently selected community rehabilitation centre in Kuching, Sarawak. **Results:** The qualitative data analysis revealed that the burden was aggravated by financial problems, multiple responsibilities hold by the caregivers, behavioural changes of the stroke survivors and lack of social support during care giving. **Conclusion:** This study highlighted the experiences by the caregivers in caring for the stroke survivors that focused on the different needs of the caregivers. Understanding these experiences may help the service providers to provide better support and resources for caregivers in caring for stroke survivors.

Keywords: Burden; Caregivers; Qualitative; Stroke; Sarawak; Malaysia

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Introduction

The operational definition of stroke was a rapidly developing sign of focal disturbance of cerebral function lasting more than 24 hours with no apparent non-vascular cause¹. Stroke is the third most common cause of death in developed countries, after coronary heart diseases and cancers. Three million women and 2.5 million men die from stroke every year worldwide². Annually, each 15 million people

worldwide suffer from stroke. Out of 15 million people, 5 million die and another 5 million are left permanently disabled causing a burden on family and community². The incidence and prevalence rates of stroke are decreasing in developed countries, but an opposite trend is taking place in the Asia Pacific, where an increasing number of patients are being diagnosed with acute stroke³. Some of the reasons that the incidence of stroke is declining in many

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developed countries are due to better control of high blood pressure and reduced levels of smoking. However, the number of strokes continues to increase in Asia Pacific because of the ageing population². Nevertheless, there has been no comprehensive database on the incidence of stroke in Malaysia⁴.

Some stroke survivors need caregivers to take care of them. After they have been discharged from hospital, they will be taken care by their own family members or other people who agree to take care of stroke survivors for a fee. A caregiver is defined as a person who lives with the patient and is most closely involved in taking care of the patients at home⁵. The caregiver is vulnerable to stress and strain such as sleep disturbance, bodily ache, financial problem and lack of time for social activities as a result of taking care of a survivor in a longer duration. The needs of a stroke survivors vary from physical activities such as walking, transfer from bed to chair, communication with family members or friends, feeding, changing clothes, emotional changes, employment issue such as loss of employment and hospital treatment payment⁶. Burden of care of stroke survivors impacts the physical as well as psychological well-being of the caregivers adversely⁷.

The burden of stroke in Asia is serious because of the increase in the aging population and the long term care need of the stroke survivors³. Partners of stroke survivors reported of experiencing care giving burden such as feelings of holding heavy responsibility, uncertainty about survivors' care needs, constant worries, limitation in social life, and dependency of survivors on their carer⁸. Stroke caregivers' mental health and the care giving duration as well as effort required by the caregivers are significant determinants of caregiver burden⁹.

Objectives

The main objective of the study was to explore the experiences of caregivers in caring for the stroke survivors.

Materials and Methods

Study settings and characteristics

This was a cross-sectional qualitative study with a view to explore the patterns of burdens and its disengagement experienced by caregivers of stroke survivors. The data was collected in the month of November 2015 until June 2016 at a conveniently selected community rehabilitation centre in Kuching, Sarawak. The study population included 18 caregivers of stroke survivors and recruitment of respondents were stopped when the data reach saturation. Healthy caregivers aged 18 years and

above, staying with patients and involved with direct care of the survivors were thus selected in this study. Interviews were done when the caregivers came to the rehabilitation centre with the patients on follow-up or at their home on request. Finally, 6 caregivers were interviewed at the rehabilitation centre and 12 caregivers were at their homes.

Data collection tools and analysis

The semi-structured interviews were conducted using a guideline to generate of dialogue discussing the difficulties and feelings experienced by caregivers during care giving. Question guidelines was developed based on Caregivers Strain Index that consists of five major domains which are employment, financial, social, time and physical. A thematic analysis was done using the procedure described by Braun and Clarke¹⁰. In the analytic process, the researchers transcribe the data first, reading and rereading the data, noting down initial ideas, followed by coding interesting features of the data into a systematic fashion, and collating data relevant to each code. After collating codes, the potential theme emerged, thus generating the thematic map of analysis. Ongoing analysis was to refine and specify each theme. Finally, the analysis tell the overall story, generate clear definitions and names for each theme.

Ethical issues

Ethical approval for this study was obtained from the Ethics Committee of Universiti Malaysia Sarawak (UNIMAS). Voluntary participation was sought, and participants were assured about the data confidentiality. They were briefed about the aims of the study and a written informed consent was obtained before each interview.

Results

Socio-demographic characteristics of the caregivers

Table 1 illustrate the socio-demographic characteristics of the caregivers. The mean (SD) age of the caregivers was 50.6 (14.3) years the minimum age was 25 years and the maximum age was 73 years. Out of 18 caregivers, 94.4% were female and the rest were male. Highest percentage had secondary level of education (38.9%) followed by bachelor's degree (16.7%). However, 16.7% had no formal education. More than two-fifths (44.4%) were currently employed and 38.9% were unemployed. Among them 11.1% have retired from a job, highest percentage of the caregivers were spouse (55.6%) followed by children (either son or daughter) comprising 22.3%.

Table 1 Socio-demographic characteristics of the caregivers

Characteristics	Frequency	%
Age of Caregiver's (in years)		
<40	3	16.7
40 - 49	6	33.3
50 - 59	3	16.7
60 - 69	4	22.2
≥70	2	11.1
Caregiver's gender		
Male	1	5.6
Female	17	94.4
Caregiver's Level of Education		
No schooling	3	16.7
Primary school	3	16.7
Secondary school	7	38.9
Diploma	2	11.1
Degree	3	16.7
Caregiver's Employment Status		
Employed	8	44.4
Unemployed	7	38.9
Retired	2	11.1
Self employed	1	5.6
Relationship with the stroke patient		
Wife	10	55.6
Daughter	3	16.7
Sister	3	16.7
Maid	1	5.6
Son	1	5.6

After data analysis, five categories of themes emerged. These include physical, social, financial, employment and time. The following sections narrated the caregiver's strains, need and psychological stress.

Themes	Subthemes
Physical	Sleep disturbance
	Forgetfulness and emotionally irritated
Social	Lack of time with friends
	Unable to attend family function
Financial	Nutritional needs
	Education
	Transport
Employment	Workplace
Time	Multiple responsibilities
	Lacking time for self

Theme 1: Physical

Stroke caregivers experience physical burden while caring for stroke survivors. They experienced sleep disturbances because they need to monitor the patients constantly especially when the patients have the urge to go to toilet. Stroke survivors may suffer forgetfulness and become easily irritated

emotionally and this can contribute to physical burden of caregivers.

Subtheme 1a: Sleep disturbance

There are caregivers who experience less sleep or disturbed sleep because they need to attend to stroke survivors' need such as need to satisfy hunger and thirst at odd hours. They also worry that the patients might fall from the bed or in the toilet. For example, one wife said;

..... "I wake up when my husband is awake because I am afraid that he will fall down. There was one night, he wanted to go to the toilet by himself, but he fell down from the bed. This is what I worried about".

(Faridah, 56 years)

A daughter described,

..... "Sometimes, I am awake because my mother wants to drink or I need to bring her to the toilet".

(Maria, 31 years)

Subtheme 1b: Forgetfulness and emotionally irritated

Caregivers not only have to experience sleep disturbance but they have to face some changes in stroke survivors such as forgetfulness and the patients become easily irritated emotionally. After the survivors were diagnosed with stroke, they cannot recall the recent event or tended to forget where they place things. Stroke survivors also become irritated emotionally, a behaviour which was not seen in the persons before suffering from the stroke. They do not want to talk much and when being asked about something, they become easily angry as claimed by their spouse. A wife expressed,

..... "My husband always forget what had happen. If I talk with him and asked him about what happened two weeks ago, he will said he forgot about it. Even if I asked him where he keep something, he cannot recall where he put it".

(Lee, 67 years)

Another wife responded,

..... "My husband becomes easily sad and he tends to be more easily irritated when I asked him something".

(Nisa, 48 years)

Stroke caregivers experienced sleep disturbance and have to deal with changes in the stroke survivors that lead to physical burden.

Theme 2: Social

Caring for stroke survivors affect caregiver's social life. They are unable to spend their leisure time with their friends or family anymore.

Subtheme 2a: Lack of time with friends

The demand from caring of stroke survivors indirectly affects caregivers as they are unable to meet up or talk with their friends as before. One of the stroke survivor's sister stated,

....."Sometimes, I cannot meet up with my friends anymore".

(Julia, 29 years)

A daughter mentioned,

....."I cannot meet up with my friends because the time that I have is needed to look after my mother and my children".

(Maria, 31 years)

Subtheme 2b: Unable to attend family function

The time needed to look after stroke survivors prevent stroke caregivers to attend any feast or dinner event at their family or friends' house. One wife expressed

....."I cannot go to school dinner or any feast at my friend's house because I need to look after my husband as he is dependent on me to go to the toilet, I need to help him while he is walking, transferring from bed to chair and feeding".

(Sarah, 43 years)

Another wife said,

..... "It is very difficult for me to go to the feast because there is no one else at home to look after my husband. All of our children are married and stay with their own family".

(Nadia, 70 years)

Caregivers were unable to have more free conversation time with their friends and unable to attend their family's event because of the need to spend time caring for stroke survivors.

Theme 3: Financial

Caring for stroke survivors affects caregivers and household in financial aspect.

Subtheme 3a: Basic needs

Caring for stroke survivors contribute to a financial burden to the family resulting from the costs of medications, diapers and supplements. A wife mentioned,

....."I have to allocate RM 400 for my husband's medication, his diaper RM 240 per month, his supplement RM 400 for two monthly. This spending disturbed the other allocation of household financial.

(Sarah, 43 years)

Another wife stated that her husband is the breadwinner before he got stroke. However, he cannot work anymore after he got stroke and his wife starts to plant paddy and vegetables for living.

....."My husband is no longer working after he fall sick. I plant paddy on my own because we cannot

always buy rice due to the expensive price nowadays. I also plant vegetables".

(Ramlah, 42 years)

Subtheme 3b: Education

One respondent stated that she sells traditional cakes to gain extra income to support her children education besides teaches in religious class for her school children as her husband is no longer able to work after the stroke. A wife noted,

....."My children are still in school and the money is not enough for them. I sell traditional cakes besides teaches Quran recitation for other children around my neighbourhood. It is still not enough for my children's school fee and other household expenses. I do not receive any help from welfare even though I ever asked for it".

(Rokiah, 56 years)

One of the respondents' children quit school because of the hardship they face after their father cannot work anymore since having stroke.

....."My youngest child still go to school and is in primary five. Second and third child do not want to go to school anymore. They quit their school when they are in Form Four. They realized that their father is unable to work anymore, so they feel that they might be a burden to the family if they go to school".

(Ramlah, 42 years)

Subtheme 3c: Transport

Respondents also reported that they have problem with transport as they need to send stroke patients for their appointment and follow up in the clinic or hospital. Some of them have difficulty sending the patients for their physiotherapy and rehabilitation session. A wife mentioned,

....."I really want to bring my husband for physiotherapy but I only have a motorcycle. I cannot always be asking help from other people who has a car to bring him for physiotherapy at the clinic. I also cannot take him with the motorcycle because he may fall down".

(Ramlah, 42 years)

Another wife said,

....."Last time, we brought my husband to do physiotherapy at the hospital but we stopped because there is nobody wants to bring him to the hospital because of no transport".

(Rokiah, 56 years)

When breadwinners of the family have stroke, the patients have to give up on their job leaving their wife or other family members to hold the responsibilities to make a living. Some of their children quit school and do odd job. The caregivers need to allocate the

money for the patients' needs, children's education and other basic needs.

Theme 4: Employment

Stroke caregivers who are employed verbalized the struggle and difficulty to do their work and caring for the stroke survivors at the same time.

Theme 4a: Work place

Caregivers of stroke survivors experience reduce concentration toward their work because they are worried about the stroke survivors who was left at home while they are at their working place. Caring for stroke survivors also affect the caregivers working performance. A wife stated,

.....*"I cannot concentrate on my work. I told Headmaster that I want to go back home for a while to look at my husband. Luckily, the distance from the school and my house is not that far"*.

(Rokiah, 56 years)

Another working wife said,

.....*"I feel taking care of a stroke husband disturb my working performance as I cannot go for a course, meeting, curriculum activities or conduct extra classes for my students. I need to send and fetch my children from school and send my husband for his physiotherapy session. My daytime is really occupied"*.

(Sarah, 43 years)

Stroke caregivers who work and at the same time need to take care of the stroke survivors found it is challenging to perform well in their work.

Theme 5: Time

Stroke care givers always have to abide with the time as there are a lot of tasks that they need to perform in a daily living.

Subtheme 5a: Multiple responsibilities

Stroke caregivers hold multiple responsibilities aside from taking care of stroke survivors. They need to send their children to school and send the patient for physiotherapy as well. A wife noted,

.....*"I really need to rush in the morning. I wake up and send my children to school, open the shop, send my children for their tuition class, manage my husband and send him for physiotherapy. I did all the works because I have to do it and nobody else. During weekend, my children help to do house chores but I do not want to burden them because they need to study and do their homework"*.

(Wee, 42 years)

A daughter said,

.....*"I have a lot of work to do. I need to manage the household, going to the farm and taking care of*

my sick father".

(Lucy, 50 years)

Subtheme 5b: Lacking time for self

Due to caring for stroke survivors, stroke caregivers experience less time for themselves because of the caring demand as well as they need to work and take care of their children. A wife responded,

.....*"I spend a lot of time to manage my husband until my time for children and myself is limited. I wake up early in the morning and manage my husband and prepare breakfast. Then, I send my children to school, send my husband to his workplace and after that I will go to my workplace. In the afternoon, I need to fetch my children from school, my husband from work and send him for physiotherapy. There are days I need to send my children for tuition class. Back at home I am tired, but I need to do house chores"*.

(Sarah, 43 years)

Caring for stroke survivors are time demanding and their caregivers spend most of their time performing the caring task and have less time for themselves. In summary, the results demonstrated that the caregivers were facing a lot of physical, social and financial challenges in managing the stroke survivors.

Discussion

In this explorative study, the researchers tried to map the caregivers need and problems encountered during care giving for the stroke survivors. Care giving is a complex process and it depends on successful residential integration¹¹. The initial part of management is critical, and the responsibilities are mainly handled by the health professional team. However, to ensure the quality of life for the stroke survivor, it depend on the caring capabilities in the home setting by caregivers. These are often ignored by health care providers. It is important that the rehabilitation team assess the situation of caregivers and assists them to manage their problems and to identify coping strategies and skills and build on successes. Stroke survivors and their caregivers may need help in adjusting their situation after the stroke event. They can share their challenges and concerns with the rehabilitation team as well as obtain help, support and cooperation to build strength and coping skills with the challenges in their life. This study found a higher proportion of caregivers experiencing a psychological strain with sleep disturbances. Previous studies indicated that care giving in the home setting faces more strain than the rehabilitation centre-based caregiving¹²⁻¹⁴. Wasserman *et al.*¹⁵ opined that no or inadequate services from rehabilitation centre or inadequate services from home setting might

cause the high prevalence of strain. The situation is worsened if the stroke affected person regains only partial independence. Enormous stresses and strains can be placed on a partner, which may cause not only sleep disturbance, but also lead to depression and anxiety. It is impossible for one person to do all the tasks of both partners. Stroke survivors can be demanding, and it is often difficult to carry on with every day activities. This hampers the maintaining of social contacts and outside interests. Although, the present study did not attempt to estimate the direct or indirect cost of stroke management both in rehabilitation and home setting, the respondents reported that they were facing tremendous economic hardship, in terms of education of their children, food, medicine and transport. Joo (2014) found that the indirect costs of stroke varied from 3% to 71% of the total cost of that event¹⁶. The study also reported that indirect cost depended on the length of types of stroke, and cost components and duration of disease. The indirect cost will increase even further with the aging population and improving survival rate of stroke patients. So, most of the indirect cost totally depends on the caregivers or from the stroke survivors. This leads to enormous economic pressure to the caregiver's family.

Limitations

Although the study had tremendous contribution to public health and social science, it is not free from limitations. The caregivers in this study were recruited from one rehabilitation centre and the sample size was limited to 18 in number. The research focused only on burdens met by stroke caregivers in Sarawak. Thus, the results may not be generalised to other settings or caregiver's population of Malaysia. Another limitation was that the caregivers were asked to recall their experiences of only stroke survivors, which may be influenced by recall bias. Furthermore, the caregivers were interviewed only once, and they were not followed for elucidation of differences in experiences. We suggest that prospective studies be conducted, using both qualitative and quantitative research designs, to understand changes of caring

experience across different stages to get the deeper understanding of caregiving phenomena.

Conclusions

This study focused on the caring experiences of caregivers of stroke survivors with different complications. Caregivers suffer from economic hardship in terms of education of their children, transport and nutritional needs for the family. However, with fruitful use of various resources, caregivers could develop the skills and techniques required to deal with the complexities of stroke. Though the caregiving process is a challenging task, in most cases, a positive and forward-looking attitude helped caregivers bridge their difficulties and continue the care. Technical support from health professionals and financial support from government is warranted. Physical and emotional support of caregiver's family members, professional, social activists is fundamental in meeting the needs of caregivers and patients alike.

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Author's contribution

MMR and ZBT: Concept and design of the study, transcribing, data analysis, manuscript writing NLS: design of the study, data collection, transcribing and data analysis. All other member authors contribute in conceptualization of the study, critical review and editing. All authors read and approved the final manuscript.

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Competing interest

The authors declare that they have no competing interests.

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