CHALLENGES AND COPING STARTEGIES AMONG INFORMAL STROKE SURVIVOR CAREGIVERS

By

NORULMUMTAZAH BINTI JOHAR

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Abstract of thesis presented to the Senate of Universiti Putra Malaysia in fulfilment of the requirement for the degree of Master of Science

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Chair : Soh Kim Lam, PhD.
Faculty : Medicine and Health Science

Most of stroke survivor caregiver need to full fill their activity daily living including stroke survivor needs. Informal stroke caregiver usually came from family. Caregivers of stroke survivor required a time for adaptation and adjustment in their life.

Most of the qualitative study had found, majority of the informal stroke survivor caregiver facing increased responsibilities, new roles and physical changes due to caregiving of stroke survivor. They also need a training to deal with the stroke survivor disability which need long time in caregiving and this time consuming activities can affect caregivers social activities.

This study is phenomenology qualitative study, using purposive and maximum variation sampling. Data were obtained using semi structured open-ended question via interview session. Thematic analysis was used to assess the experiences of informal stroke caregivers. This study provided 20 participants of informal stroke caregivers which are over a period of 6 months post discharge from hospitalization.

Three major themes were found in this study. (1) Challenges in caring stroke survivor (2) Limited available support in caregiving. (3) Caregivers coping strategies. This study concludes that informal stroke caregivers used more time and energy in order to manage stroke survivor.

Abstrak thesis yang dikemukakan kepada Senate Universiti Putra Malaysia
sebagai memenuhi keperluan untuk ijazah Master Sains

CABARAN DAN STRATEGI MENANGANI MASALAH DIKALANGAN PENJAGA PESAKIT STROKE

Oleh

NORULMUMTAZAH BINTI JOHAR

Mei 2019

Pengerusi: Soh Kim Lam, PhD.
Fakulti: Perubatan dan Sains Kesihatan

Kebanyakkan penjaga pesakit stroke perlu memenuhi keperluan harian diri sendiri dan pesakit stroke. Kebanyakkan penjaga pesakit stroke terdiri dari ahli keluarga. Mereka memerlukan masa untuk menyesuaikan diri dan melakukan perubahan dalam hidup mereka.

Majoriti kajian kualitatif mendapati kebanyakkan penjaga pesakit stroke menghadapi penambahan tanggungjawab, peranan baru dan perubahan fizikal semasa menjaga pesakit stroke. Mereka juga memerlukan latihan untuk mengendalikan pesakit stroke, ia memerlukan lebih masa untuk menguruskannya. Keadaan ini memberi kesan kepada aktiviti social penjaga pesakit stroke.

Kajian kualitatif yang menggunakan kaedah sample purposive dan sample criterion. Pengumpulan data dilakukan melalui kaedah temubual dengan soalan terbuka semi-struktur. Kaedah thematic analysis digunakan untuk menganalisa data. Kajian ini disertai 20 penjaga pesakit stroke yang telah keluar dari hospital lebih daripada 6 bulan.

Tiga tema iaitu: (1) Cabaran yang mungkin memberi kesan kepada kualiti hidup penjaga pesakit stroke. (2) Kurang sokongan dalam penjagaan pesakit stroke. (3) Cara penjaga pesakit stroke menangani masalah. Kajian ini mendapati penjaga pesakit stroke menggunakan lebih masa dan tenaga untuk menguruskan pesakit stroke.

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Finally, a very special thank you to the caregivers who took the time out of their busy schedules to shine light on the interview session. It is through their devotion that this study became a reality.

I certify that a Thesis Examination Committee has met on 28 May 2019 to conduct the final examination of Norulmumtazah binti Johar on her thesis entitled “Challenges and Coping Strategies Among Informal Stroke Survivor Caregivers” in accordance with the Universities and University Colleges Act 1971 and the Constitution of the Universiti Putra Malaysia [P.U.(A) 106] 15 March 1998. The Committee recommends that the student be awarded the (insert the name of relevant degree).

Members of the Thesis Examination Committee were as follows:

Huzwah Binti Khaza’ai, PhD
Senior Lecturer
Faculty of Medicine and Health Sciences.
Universiti Putra Malaysia
(Chairman)

Ismi Arif Bin Ismail, PhD
Associate Professor
Faculty ofEducational Studies
Universiti Putra Malaysia
(Internal Examiner)

Khatijah Abdullah @ Lim Geok Lim, PhD
Professor
Department of Nursing Sciences
Faculty of Medicine
University Malaya
(External Examiner)

ROBIAH BINTI YUNUS, PhD
Professor and Deputy Dean
School of Graduate Studies
Universiti Putra Malaysia

Date: 4 September 2019

This thesis was submitted to the Senate of Universiti Putra Malaysia and has been accepted as fulfilment of the requirement for the degree of Master in Nursing. The members of the Supervisory Committee were as follows:

Soh Kim Lam, PhD
Associate Professor
Faculty of Medicine & Health Science
Universiti Putra Malaysia
(Chairman)

Rosliza binti Abdul Manaf, PhD
Associate Professor
Faculty of Medicine & Health Science
Universiti Putra Malaysia
(Member)

ROBIAH BINTI YUNUS, PhD
Professor and Dean
School of Graduate Studies
Universiti Putra Malaysia

Date:

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- the research conducted and the writing of this thesis was under our supervision;
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Signature:
Name of Chairman of Supervisory Committee: Assoc. Prof.Dr. Soh Kim Lam

Signature:
Name of Member of Supervisory Committee: Assoc. Prof. Dr Rosliza binti Abdul Manaf

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LIST OF ABBREVIATIONS

QOL	Quality of life
ADL	Activity daily living
MOH	Ministry of Health, Malaysia
NGO	Non-government organization
WHO	World Health Organization

CHAPTER 1

INTRODUCTION

1.1 Background of the study.

Stroke is defined as a clinical syndrome consisting of rapidly developed signs of focal disturbance of cerebral function, lasting more than 24 hours," (Wolff, Boss, Murad, Franco, Krestin, Hofman, Vernooji & Van der Lust, 2016). Stroke is one of the leading causes of disability among Malaysians. In 2013, stroke was the second most common cause of death (11.8% from all death) worldwide and the third most common cause of disability (4.5% from ischemia diseases). Stroke is a well-known major public health concern due to a large number of deaths and long-term disabilities associated with it (Lijing, Chao, Jie, Jaime, & Lio…et al. 2016). Globally, approximately 16.7 million people suffer from stroke annually and an estimated 6.9 million of these individuals die due to stroke complication (World Health Organization, 2012).

The two main types of stroke are ischaemic stroke and haemorrhagic stroke. Ischaemic stroke includes embolic stroke and thrombotic stroke, approximately 80% of all cases are caused by blockages in arteries due to the blood clot. Haemorrhagic stroke is caused by bleeding into brain tissue when a blood vessel is burst, approximately 20% of all cases (El-Masry, 2010). Asia has higher vascular risk factor overall, 60% of the world's total mortality due to stroke occurs in East Asia (Mehndiraata, Khan, Mehndiratta,P & Wasay, 2014; Ohira & Iso, 2013).

While, in Malaysia, it is estimated that 19200 patients with stroke are hospitalizedannually and 22.62% of 19 200 deaths in the government hospital in 2016. While in Johor, approximately 19.8% suffered from stroke due to non-communicable diseases such as diabetes mellitus, hypertension and cardiovascular accident (Ministry of Health Malaysia, 2017).

Despite increasing stroke mortality, much of stroke burden arises from disability (Ferri, 2011). Among those who survive, almost 60% of patients live with permanent disability (Scherbakov & Doehner, 2011) such as loss of hearing, loss of speech and blur vision which are the major types of disability (Scherbakov, Von, Anker, Dirnagl & Doehner, 2013). Stroke survivors experience significant functional limitations resulting from decreased mobility, cognitive impairment, depression and personality changes (Rigby, Gubitz & Phillips, 2009). Stroke does not only affect the patients but it can also a challenge for their family members (Thrush & Hyder, 2014).

Nurses are uniquely positioned to provide multidisciplinary, innovative holistic approaches in taking care of stroke survivor. Wellness is a very important area of stroke care and opportunity for research. According to the National of Medicine and the Robert, Wood Johnson Foundation released The Future of Nursing: Leading Change, Advancing Health (2010), reported that nurses should be full, active partners in health care of stroke survivor. In light of this development, caregiver of stroke survivor should be can be on behalf of the continuity of care of the stroke survivor at home. A caregiver is defined as a person who lives with the patient and most closely involved in taking care of him/her.

The two types of caregiver are the formal caregiver and informal caregiver. Formal caregiver is a professional trained of caregiver and they are paid in caregiving. Some of these formal caregivers have their own organization such as nursing home, they also can be a nurse who was paid to taking care of stroke survivor. An informal caregiver is defined as ‘unpaid person who helps with the physical care or coping with the disease' (Bhattacharjee, Vairale, Gawali & Dalal, 2012). The informal caregiver is anyone who provides any type of physical and/or emotional care for an ill or disabled loved one at home. Loved ones are those in need of care, could be suffering from physical or mental illness, disability, substance misuse, or other conditions.

In 2009, there was an estimate of 65.7 million individuals in the United States who served as informal caregivers. Unpaid caregivers or informal caregivers are the main sources of manpower whose provide as much as 90% in-home long-term caregiving of the stroke survivors (National Alliance, 2014). Recent years have seen an increase in informal caregiving in Malaysia due to the increasing incidence of chronic and degenerative diseases including diabetes, hypertension, cardiovascular illness, and stroke (Phua, 2009). There are different types of family caregivers such as parents, adult children, spouses, family members, neighbors and friends (Vincent, Desrosiers, Landreville & Demers, 2009). Typically, informal stroke caregivers have a marriage relationship with the individual such as parents, adult children, spouses, or family members (Vincent et al., 2009). The majority of the informal stroke survivor caregivers are women but there is a gradual upward trend of male counterparts in recent years (Cranswick & Dosman, 2008).

Regardless of how they become caregivers, they are about to take on a new role for which they may not be prepared (Luker, Murray, Lynch & Bernhardson, 2017). It is normal for them to feel nervous or overwhelmed about what is expected of them. They may experience a number of mixed emotions including anxiety, anger, and sadness (Khaw et al. 2017). At the same time, they will probably feel the desire to care for their loved ones the best way they can.

By the time the hospital discharges a stroke patient, the caregiver will often find themselves having to perform new and unfamiliar tasks. The caregiver has to balance the dual responsibility of looking after a disabled stroke survivor and caregivers' daily activities. These may include giving medicine, assisting with meals, and performing medical and nursing procedures such as personal care, emotional support, medical care, household management, supervision, and translation services in a medical setting. All these are a challenge and the new environment for the informal caregiver to cope with. The level of distress in family carers of individuals with the disability can be high (Clay, Grant, Wadley, Perkins, Haley & Roth, 2013) and this is associated with increased morbidity and mortality.

Providing care may be highly challenged, demanding and a potentially harmful effect of life distress as experienced by the stroke survivor caregivers due to the complex nature of stroke consequences including physical, emotional, cognitive and behavioural changes (Jaracz, Fudala, Gorna, Jaracz J, Moczko & Kozubski, 2015). Consequently, most of the informal caregivers are often unprepared and lack the information and skills they need for a successful recovery. Being in thissituation which is debilitating and chronic in nature, caring for a stroke survivor can indeed burden the caregiver. There are decreasing support services offered in the community (Pindus, Mullis, Lim, Wellwood, Rundell, Noor Azah & Mant, 2018) and the ever-aging population and an increased incidence of stroke (WHO, 2017). Caregiving of stroke survivor is a challenge for stroke survivor caregiver.

Considering that stroke survivors require long care and that adverse effect of caregiving may also be long-lasting, this study would provide additional insight into the evolution of caregiving and would help identify those individuals at risk of substantial burden. Therefore, it is important to identify the factors of the caregivers' challenge and their coping strategies to handle this prolong situation. The results would hopefully provide insight to healthcare personnel in developing a support program for informal caregivers and stroke survivors after discharge.

1.1 Problem statement.

The community has been exposed to professional, caring and teamwork culture in the caregiving. Society believes that this culture is a way of helping each other and alleviating the burden of each other. Informal caregivers are accountable for catering the first-ever stroke survivors' needs as well as maintaining both functional improvements gained in rehabilitation and long-term well-being of stroke survivor. Therefore, the informal stroke survivor caregivers' expect help from a healthcare provider, family and friend support to face the challenges in the caregiving of stroke survivors.

Informal stroke survivor caregivers faced various challenges while providing caregiving to the stroke survivor after hospitalization. Informal caregivers are accountable for providing for the first-ever stroke patient needs, including maintaining functional improvement gained in rehabilitation and the long-term well-being of the stroke patients.

Physical changes associated with stroke impact the caregiver as well as the stroke survivor. These changes affect the health and lifestyle of informal caregivers. The majority of caregivers reported they had physical disorder after engaging in caregiving duties (Kamal, Bond & Froelicher, 2014). However, this opinion is only based on external aspects regardless of the internal factors of the challenge in the care of stroke patients. This is because the individual is highly influenced by the environment and stroke survivor behavior.

Above opinion was supported by Khaw et al., 2017 & Nydevik, 2003, these caregiving responsibilities are emotionally challenging, especially for a person who has not had any prior training in carrying these roles and responsibilities. The drastic changes in lifestyle due to stroke survivor behavior and disability can make the caregivers suffer from depression (Abu Kamel, Bond & Froelicher, 2014).

According to Qiu, Sit & Koo (2017) also found that caregiving of stroke survivor related to a series of health issues because caregiver may ignore their own health status to full fill their caregiving responsibilities. Most of the stroke survivor caregiver also complained, they did not receive healthcare support in caregiving of stroke survivor at home (Qiu, Sit & Koo, 2017). Informal stroke survivor caregivers are manpower in taking care of stroke survivor and they also continuing nurse's role after discharge from hospitalization (Burch, Rice & Barr, 2017).

Regarding this situation, informal stroke survivor caregiver should receive holistic care and wellness approach to help them achieve speed recovery for stroke survivor and to maintain caregiver health. The findings in research done by Burch et al. (2017), show that the caregiving has detrimental effects on the lives of caregivers and that they are insignificant need social support to help them deal with caregiving task and responsibilities.

According to The Second Burden of Disease Study for Malaysia, published by the Institute of Public Health in 2012, approximately 19.8% of the Johorean will suffer from non-communicable diseases complications including disability and death. The informal stroke survivor caregiver will increase as well as the increase of incidence of non-communicable diseases such as diabetes mellitus, hypertension, and cardiovascular accident. Supported by the study in Caregiving as a Risk Factor for Mortality: The Caregiver Health Effect Study, caregivers who providing care and experiencing strain had mortality risk than were 63% higher than caregivers who providing care and not experiencing strain (Schulz & Beach, 2000)

Regarding this situation, this informal caregiver needs a support system to help them in caregiving of stroke survivor, but currently there still less support service for the informal stroke survivor caregivers in Johor (NASAM, 2010). Too little attention for supporting roles of informal stroke survivor caregivers after hospitalization and very few multi-dimensional programs for stroke survivor caregiver handling the stroke survivor. More than that, there were limited studies done about stroke survivor challenge and their coping strategies (Pindus et al., 2018).

The implication of above situation, the ability of an informal stroke caregiver to cope with the challenge, exposes the ability of healthcare provider in delivered health education and other support systems to the caregiver during discharge as well. This is supported by Pindus et al. 2018, the informal caregiver responsibilities are continuing caregiving of the healthcare provider during warded until home.

In conjunction with the above phenomena, concluded that informal caregivers need help and a great deal of time in caregiving of stroke survivor. Hereby, this study aims to understand, describe and discover the challenge of stroke survivor caregiver and to access their coping strategies.

1.3 Research question.

1.3.1 Central question.

What is the actual challenge for a stroke survivor caregiver?

1.3.2 Sub-question script

What are the factors that influence caregivers’ challenge?

“How would the stroke caregivers’ describe their challenge? “

"What happened to stroke caregivers' life while providing caregiving for stroke survivor?"

“How the stroke caregivers’ coping with the challenge in caregiving for the stroke survivor?”

These all we have to know what the caregivers facing in taking care of stroke survivors. Because of this, the present study has chosen to use a qualitative study to investigate the topic. An in-depth unstructured interview approach will yield findings that can provide a valid understanding of caregivers’ burden.

The knowledge generated by such thematic study will offer a foundation for future psychological/ educational intervention studies involving caregivers. Moreover, it will enhance the evidence-based knowledge available to clinicians in order to effectively support families (Penner, 2008).

1.4 Purpose of the study.

Caring for stroke survivor leads to caregiving strain. The purpose of this study is to understand, describe and discover the burdens of caregiver for stroke survivor at home and to explore their coping strategies.

1.5. Operational definition

1. Stroke caregiver :
   The person primarily responsible for providing and/or coordinating stroke survivor care in the community, without nursing skill or financial compensation. The informal caregiver maybe a friend or relative of the patient.

2. Stroke survivor :
   A person who has endured a stroke (irrespective of the type or location in the brain), who may suffer residual physical impairment, cognitive impairments, behaviour changes, and/or difficulty in performing activities of daily living which is fully discharged from hospitalization more than 6 months.

3. Caregiving :
   Providing care for stroke survivors in daily living activities (e.g. sponging, eating, defecation, and giving medicine) and psychological needs.

4. Informal caregiver :
   A primary person who provides caregiving to a stroke caregiver at home (e.g. family members, neighbour, friend, spouse).

5. Caregiver burden :
   Subjectively assess the problems faced in the care of stroke survivor at home (e.g. financial, physical disorder, lack of knowledge).

6. Discover :
   Deepened thoroughly about informal stroke survivor caregivers' burden.

7. Describe :
   Explain and elaborate on the experience and way of life of the informal stroke survivor caregivers and their coping strategies.

8. Coping strategies :
   How the stroke caregivers deal with the problems encountered, to help the caregiver to elevate the caregivers' problems (e.g. financial, emotional, and tangible).

9. Data saturation:
   A methodological principle which states that further interviews no longer serve to add new data, signalling additional data collection is unnecessary. The informant keeps on giving the same information.

10. Maximum variation sampling:
    Select participants with diverse characteristics.

11. Mental health:
    Mental status is seen from a change of attitude and dislike of feelings.

12. Physical health:
    Any change in health according to complaints from caregivers.

13. Tangible resources:
    Assistance equipment or self-care aid for stroke survivors (e.g. wheelchair, commode, ripple mattress).

14. Enumeration: The frequency with which code appears in the data.

15. Hemiplegia: Paralysis of one side of the face and body.

16. Hemiparesis: Weakness of one side of the face and body.

17. Incontinence: Uncontrolled bowel and bladder.

18. Lethargic: Very tired.

19. Dressing: Wound cleaning.

20. Continuous Bladder Drainage: Patient wearing catheter to pass urine.

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