Education Quarterly Reviews

Mahalle, S., Yahya, N., & Zailani, F. F. (2022). Psychological Issues on Family Caregivers of Stroke Patients in Brunei Darussalam: In the Era of Pandemic Covid-19. *Education Quarterly Reviews*, 5(2), 299-305.

ISSN 2621-5799

DOI: 10.31014/aior.1993.05.02.490

The Asian Institute of Research
Education Quarterly Reviews
Vol.5, No.2, 2022: 299-305
ISSN 2621-5799

DOI: 10.31014/aior.1993.05.02.490

Psychological Issues on Family Caregivers of Stroke Patients in Brunei Darussalam: In the Era of Pandemic Covid-19

Salwa Mahalle[1], Nordiyana Yahya[2], Fifi Faulina Zailani[3]

[1,2,3] Sultan Hassanal Bolkiah Institute of Education, Universiti Brunei Darussalam

Correspondence : Salwa Mahalle, Sultan Hassanal Bolkiah Institute of Education, Universiti Brunei Darussalam, Brunei. Email : salwa.mahalle@ubd.edu.bn

Abstract
Family caregivers play an important role in providing main support for family members with a disability in order for them to function normally in their everyday life. The main goal of this research study is to promote psychological health awareness of stroke family caregivers in Brunei Darussalam, especially during the pandemic of Covid-19. This study concentrated particularly on long-term family caregivers who provide care to stroke family members who were severely affected by the disease that caused them to heavily depended on their family caretakers. This qualitative research involves interviewing 8 locals participants using snowballing sampling and a thematic analysis approach that investigate thoroughly the challenges and identifies the needs required by family caregivers in Brunei. The findings of the study discovered that all family caregivers experience psychological issues such as 'Depression' and 'Stress' and are in need of family support and self-care to reduce challenges they experience such as emotional exhaustion, physical problem, sleep deprivation, financial issues, and accessibility to basic needs in caregiving.

Keywords: Caretaker, Stroke Patients, Psychological Issues

1. Introduction

This research study focuses on the mental health wellbeing of family caregivers of Stroke patients in Brunei Darussalam. A stroke is a form of chronic disease that is caused by a lack of oxygen due to the blockage of blood flow to the brain (American Psychological Association, 2010). According to the World Health Organization, stroke is one of the main causes of death worldwide aside from heart disease, cancer, and Diabetes. There are more than 300 people experience a stroke in Brunei Darussalam and the majority of these individuals are aged 65 years old and above (Anuar Rambli, 2017). Two-thirds of these individuals with stroke claimed to be non-recoverable, meaning they will lose their self-ability to function normally in their everyday lives, hence, the need for ongoing support from their family members who are expected to take the role of a caregiver. Family caregivers also referred as informal carers (Payne, Smith, & Dean, 1999) act as a backbone for stroke patients, as they are expected to be the main source of support for an individual that lost their ability to carry out their normal or everyday routine. Having said that, Bakas and Commiskey (2021) asserted that family caregivers are often found to lack essential skills in terms of caregiving such as lack of knowledge and training, and access to required services and resources which makes caregiving not easy for many.

By definition, caregiving is often observed as a process of activities and responsibilities to be carried out to meet the physical needs of patients whilst providing them with emotional, social, and financial support (Gorgulu, Polat, Kahraman, Ozen, & Arslan, 2016). The act of caregiving almost seems to be part of one's job as it usually entails long time commitment and multiple responsibilities particularly for patients who needs long-term care (Tsai, Yip, Tai, Lou, 2015). The transition to long-term care happens when the caregivers' care needs are found to exceed the family caregiver's capacities (Anderson, Parmar, Dobbs, & Tian, 2021). Usually stroke survivors require long-term caring due to the pervasive physical immobility which leads to high dependency on caregivers.

There has been a substantial amount of research studies conducted to examine the effects or impacts of long-term caregiving with caregivers of stroke patients over the decades. Previous studies have examined impacts on the well-being of the longtime caregivers of stroke patients in terms of physical and mental health (Saban, Serwood, DeVon ad Hynes, 2010; Salter, Zettler, Foley, & Teasell, 2010), emotional and psychological stability (Han & Haley, 1999; Menon, Salini, Habeeba, Conjeevaram, & Munisusmitha, 2017), self-confidence and efficacy and how they perceived their role as caregivers (Sheth, Lorig, Stewart, Parodi, & Ritter, 2021). It has been reported that inevitable long depression, poor quality of social life, as well as persistent health problems are adverse effects experienced by caregivers of long-time stroke patients.

The recent event which witnessed the Covid-19 pandemic has certainly led to changes in people's lives. For caregivers of long-term patients, the changes may mean intensifying the hardship of caregiving on their existing conditions of their wellbeing. An inevitable surge of studies cropped up in the literature amidst the pandemic examining the kinds of problems and challenges faced by the caregivers of patients with life-long conditions (for example, dementia – Harris & Titler, 2021; Rainero, Bruni, Marra, Cagnin, Bonanni, Cupidi et al., 2021; cancer – Zeng, Cao, Zhao, Li, & Hou, 2021). Anderson and colleagues (2021) conducted a study with 604 family caregivers in the province of Alberta, Canada reported that the pandemic had affected the participants' emotional stability and mental health. The findings found that the caregivers were either feeling overwhelmed in taking care of their sick family members at home or felt anxious or worried when they were restricted from caring for their sick family members in health or care centers.

1.1. Studies on the impacts of family caregiving on stroke patients during the pandemic

Despite the limited studies reporting on caregivers of stroke patients found in the literature, there has been only quite a handful reporting on the impacts of covid-19 on the caregiving of stroke patients and certainly, not many that examine the psychological impacts (for example; Lee, Tsang, Yang, Kwok, Lou & Lau, 2021; Sutter-Leve, Passint, Ness, & Rindflesch, 2021), and on the kinds of provisions for psychological support interventions for caregivers (see Bertuzzi, Semonella, Bruno, Manna, Edbrook, et al., 2021 for review).

A study conducted by Lee et al. (2021) with 25 stroke patients' family caregivers in Hong Kong reported that the caregivers who had taken care of the patients for more than a month during the pandemic, experienced an additional workload in caring for the patients since the patients would have to spend more time at home instead of at care-centers which were closed during the pandemic. The additional workload and 24-hour care at home are observed as major determinants of stressful life that affect the relationship of the family caregiver with the patients leading to an increase of inevitable physical harm and verbal abuse. The study also revealed that the caregivers experienced 'worsened physical and psychological wellbeing because of increases in care burden with simultaneously reduced formal and informal support' (p. 1407). In terms of psychological wellbeing, the study reported that the caregivers expressed their frustration and anger when performing care tasks resulting in unwarranted stress and burnout. Apart from the stress from taking care of the patients, the caregivers indicated that they were also worried about getting infected by the diseases which might deter them from playing their roles as caregivers to the patients who are often their immediate family members. The study also pointed out the need for effective measures to address psychological distress such as providing support such as ‘cognitive behavioral therapy, psychoeducation, and counseling’ (p. 1412).

Sutter et al. (2021) conducted a study with 11 caregivers of newly acquired stroke patients in the USA. The qualitative study examined the stress level of the family caregivers and how Covid-19 impacted the experience of the family caregivers of patients with newly-acquired stroke who were confined in an inpatient rehabilitation setting. The findings revealed that the increase in the stress level of the family caregivers was resulted from not being able to know about their ill family member who was not under their care, fear of recurrent stroke and safety following discharge home, not being able to receive frequent updates from the rehab centers as well as not being able to communicate with their ill family member who suffered from speech or cognitive impairment due to stroke. The study also underscored alternatives measures to ensure the direct involvement of the caregivers in the caring of the stroke patients.

From the studies mentioned here, psychological issues during the pandemic can be identified under the circumstances of direct involvement of the family caregivers in caring for the stroke patients at home and the failure to find time for themselves. On the other hand, the absence of direct contact or involvement in caregiving is shown to lead to emotional problems.

The consequences of stroke do not only affect individuals that suffered from it, studies have also shown that they put significant impacts and changes on the lives of the family caregivers even during the era of pandemic Covid-19 where the pressure faced by the patients as well as by the family caregivers would heighten. Although some individuals may experience positive outcome in handling stroke patients, scholars such as Muller-Kluits et al. (2018), Adelman et al. (2014) and Kurtz et al. (2004) argue otherwise, these scholars found that the illness increase burdensome and intensified the levels of stress towards family caregivers. With long hours of caregiving and overwhelming effort dedicated to managing and support stroke patients, it is undoubtedly that caregivers are more likely to be at risk for psychological distress. This qualitative research study will explore thoroughly on the challenges faced, strategies used and requirements needed to improve the lives of family caregivers of stroke patients.

The main aim of this research study is to promote the psychological health awareness of stroke family caregivers. To achieve the main goal of this study below are the listed objectives:

- To identify the issues faced by stroke family caregivers by conducting a semi-structure interviews.
- To recognize the experiences and coping mechanisms used by family caregivers when dealing with psychological issues for example, stress, anxiety and depression.
- To explore what are the needs and recommendations suggested by family caretakers with the purpose of providing helpful information for readers, especially family caregivers whom are dealing with psychological problems.

2. Method

The research methods that were used to conduct this research study a qualitative-based design with descriptive phenomenology approach using semi-structure interviews. Descriptive phenomenology methods are commonly used to collect data in social science studies mainly in medical and health research areas (Davidsen, 2013).

2.1 Participants and Research Sampling

There are a total of six participants, three males and three females who were recruited using snowballing sampling. This research study requires family caregivers that have been giving care to stroke patients for more than 3 years, this is due to the long-term caregiving experience of the family caregivers. On the other hand, professional caregivers such as nurses, doctors, therapists, teachers, and specially trained volunteers will not be included in this study, mainly because the study focuses on non-paid and non-health professional family caregivers who provide daily care to stroke patients at their own residence.

2.2 Pilot Study

A pilot study was carried out in this research study to ensure all the interview questions were valid and reliable for the actual study. The pilot study consisted of two participants, a male, and a female, which were recruited using snowballing sampling.

3. Results

3.1 The Psychological Issues Experienced

Many of the participants emphasize 'depressed' as the main form of psychological challenges they experience while giving care:

"*Oh! Many times to be honest! I often feel depressed and stressing out over everything and before I experience suicidal thoughts, mostly because I couldn't accept where I am now…"* (**Informant 1**)
"*….I don't know like I feel depressed at some point…seeing my mother like this, how I am judged by my other family members, how I spend most of my time for my mother even though I am married…"* (**Informant 2**)
"*Ehh always and only god knows, I feel stress, headache, feeling uneasy, depressed after years of giving care…." (*(**Informant 3**)

3.2 Other challenges faced by caregivers

a) Lack of other family support

Researcher discovers majority of the participants required their other family members to help and support them doing their daily caregiving routine. However, in some cases researcher also learned that some of the participants have no one to rely on when providing care to their stroke family members:
"*…because now both my children are married it's hard for them to take care of their mother so it's just me…*" **(Informant 3)**

Three of the participants shares that they suffered from muscle pain and backache from giving care to their family members:

"*…I do experience back ache and muscle sore from carrying my dad to his bed or to his wheelchair, imagine having to do this daily…"* (**Informant 1**)

"*…sometimes I feel like I can't stand it because my back hurts carrying her to the bed to the chair and to the dining table…."* (**Informant 3**)

"… her body is getting stiff too lately so it's difficult to carry her around my body ache too…" (**Informant 2**)

b) Financial needs

Another rising issue stated by family caregivers in the actual study was the financial challenges that they experienced. Daughters from the interview session express their concerns on financial support:
"*…perhaps an allowance if possible, travel allowance to be specific for gas, kitchen groceries, I believe it is not just me, but most caregivers in Brunei we are unemployed and rely on pension money or financial support from other family members…*" (**Informant 1**)

"*…financial issues sometimes, I mean there's a lot to be spent on, like diapers, milk, medication from private clinic and his necessity like sleeping pad, shampoo…"***(Informant 4**) *c) Transportation problems*

Another issue that was raised was transportation problem, one daughter expressed her worries on not having any transportation to bring her grandfather for his hospital appointment:
"*...I believe they think that we are lazy to go, but we don't have any transport, my mom is working, we only have one car, I couldn't afford to booked rental cars too….*" (**Informant 4**)

d) Sleep deprivation

In the findings, researcher also found two participants having trouble to sleep after many hours of giving constant care to their stroke family members:
*"…I can't sleep well at night I kept having muscle pain and back ache, but I am thankful to have my mom here with me for emotional support…" (***Informant 1***)*

"I'm having difficulty to sleep at night, even during the day, I think too much, I'm always worried, but most of the time it was just about taking care of my father and thinking about what my future holds…" (**Informant 5**)

e) Emotional issues

Similar to the main psychological issues, 4 out of 6 participants in the actual study express their feelings deeply during interview while describing the issues that they experience:

"…like seeing my sibling they are working, having children, when will it be my time? I am the eldest I want to be happy too, I am 36 years old now and I feel like I'm still figuring out what to do with life" (Aminah)
"…the most challenging part is usually my in laws or my other families, they tend judge me…like I don't have any children because I am stress taking care of my mother, that I am not working and always depend on my husband's money and all sometimes that actually drains me, uh…. Drains my energy" (Mariam)

f) Effect relationships with family

Similar to the findings in the pilot study another main issue is how caregiving affect family caregivers of stroke patients to have issues with their other family members:
"…. I don't know like I feel depressed at some point especially when I fought with my husband if he doesn't understand that I have to do something for my mom…" (**Informant 2**)

3.3 Coping Mechanism Practiced by Family Caregiver in Reducing Psychological Issues

In the findings from the actual study interviews, participants mentioned they mostly rely on religious support, problem-solving skills, outdoor activities, medication, socialize with others, and having self-time:
"*I pray, recite prayers and make myself busy doing chores, I think it is important not to leave our prayers too because that is the only time you can express all your feelings of burden to Allah*" (**Informant 1**)

"*I usually cook when I'm stressed, I watch Netflix with my mom… talk to my sister… video call with my siblings…*" (**Informant 2**)

3.4 The needs for Family caregivers to improve their well-being as a Caretaker

- Family support

"*Alright for me… family, if there's no family support it will make the caregiving experience more challenging.*"
(Informant 2)
"*…I think that it is important to have family around, even if they have their own lives, be more considerate to your elderly parents, be more understanding.*" (**Informant 3**)

- Self-time

"I think what we need as a caregiver is time for ourselves, I don't know but ever since I give care to my dad I barely have time for myself, he became my priority" (**Informant 1**)

"*For me… making an effort is important, not just for the person you taking care of but make an effort to focus on your own health too, eat healthily, do exercise...*" (**Informant 3**)

- Awareness

'*…as a caregiver I think it is important for other people to understand that it is not easy doing what we do daily, and I think your study is unique because you are making an effort to share our voices that are often ignore by many…*' (**Informant 2**)

- Intervention programme and counselling services

"*I think it would be a miracle if Brunei were to have a form of community services especially for us caregivers, I believe we can learned from each other to ease off our burden…*' (**Informant 2**)

" *I think what I really need is counselling, I really want to figure out ways on how to better myself, not to get overstress on little things…*" (**Informant 4**)

4. Discussion

From the results of the findings, it is clear that psychological issues (stress and depression) experienced by family caregivers of stroke survivors do influence their caregiving behaviour. According to Dr. Teri Kennedy, who specialized in the health risks for family caregivers at Arizona State University, the feeling of depression and stress are common among caregivers especially among younger adults or adults themselves as they are more prone to low self-esteem, lack of social support and personal time (Kennedy, 2016).

There are many other challenges experienced by family caregivers apart from psychological distress, this includes the seven recorded findings such as lack of other family support, physical pain, financial needs, transportation problems, sleep deprivation, emotional issues, and effect relationship with other family members. Similar to Bevans and Sternberg's research study on caregiving burden and health effects of family caregivers of chronic patients, the challenges that are highly agreed on were sleep deprivation, financial issues, lack of strong support system and intense caring and over-dependency (Bevans & Sternberg, 2012).

Family caregivers, especially the long-term family caretakers who dedicated their time and energy to providing care to chronic patients at home are no exception to receiving full support from different groups of people, especially from medical practitioners and society. It is also important that family caregivers are able to find coping strategies that could help them in their daily caregiving routine. For instance, as mentioned in the result findings above, acceptance, spiritual support, problem-solving skills, medication, making an effort for the family caregiver's own health, and self-time became some of the strategies that family caretakers believe would help them to survive in the long run. In a country such as the United States of America, scholars such as William et al. (2014) found that not only do family caregivers in Toronto need their family support in caregiving but formal supports were also imperative for family caregivers such as planning ahead, joining intervention programme and promote awareness.

Acknowledgment

Special thanks are dedicated to all respondents involved in this study, for committing their time to be interviewed.

References

Anderson, S., Parmar, J., Dobbs, B., & Tian, P. G. J. (2021). A tale of two solitudes: Loneliness and anxiety of family caregivers caring in community homes and congregate care. *International journal of environmental research and public health*, *18*(19), 10010.

Bakas, T., & Commiskey, P. (2021). Stroke Family Caregiving and the COVID-19 Pandemic: Impact and Future Directions.

Bertuzzi, V., Semonella, M., Bruno, D., Manna, C., Edbrook-Childs, J., Giusti, E. M., ... & Pietrabissa, G. (2021). Psychological support interventions for healthcare providers and informal caregivers during the COVID-19 pandemic: a systematic review of the literature. *International journal of environmental research and public health*, *18*(13), 6939.

Gorgulu, U., Polat, U., Kahraman, B., Ozen, S., & Arslan, E. (2016). Factors affecting the burden on caregivers of stroke survivors in Turkey. *Medical Science and Discovery*, *3*(4), 159-65.

Han, B., & Haley, W. E. (1999). Family caregiving for patients with stroke: review and analysis. *Stroke*, *30*(7), 1478-1485.

Harris, M. L., & Titler, M. G. (2021). Experiences of Family Caregivers of People with Dementia during the COVID-19 Pandemic. *Western journal of nursing research*, 01939459211055773.

Lee, S., Colditz, G. A., Berkman, L. F., & Kawachi, I. (2003). Caregiving and risk of coronary heart disease in US women: a prospective study. *American journal of preventive medicine*, *24*(2), 113-119.

Lee, J. J., Tsang, W. N., Yang, S. C., Kwok, J. Y. Y., Lou, V. W., & Lau, K. K. (2021). Qualitative study of Chinese stroke caregivers' caregiving experience during the COVID-19 pandemic. *Stroke*, *52*(4), 1407-1414.

Menon, B., Salini, P., Habeeba, K., Conjeevaram, J., & Munisusmitha, K. (2017). Female caregivers and stroke severity determines caregiver stress in stroke patients. *Annals of Indian Academy of Neurology*, *20*(4), 418.

O'Connell, B., & Baker, L. (2004). Managing as carers of stroke survivors: strategies from the field. *International Journal of Nursing Practice*, *10*(3), 121-126.

Payne, S., Smith, P., & Dean, S. (1999). Identifying the concerns of informal carers in palliative care. *Palliative medicine*, *13*(1), 37-44.

Rainero, I., Bruni, A. C., Marra, C., Cagnin, A., Bonanni, L., Cupidi, C., ... & SINdem COVID-19 Study Group. (2021). The impact of COVID-19 quarantine on patients with dementia and family caregivers: a nation-wide survey. *Frontiers in aging neuroscience*, *12*, 507.

Saban, K. L., Sherwood, P. R., DeVon, H. A., & Hynes, D. M. (2010). Measures of psychological stress and physical health in family caregivers of stroke survivors: a literature review. *Journal of Neuroscience Nursing*, *42*(3), 128-138.

Salter, K., Zettler, L., Foley, N., & Teasell, R. (2010). Impact of caring for individuals with stroke on perceived physical health of informal caregivers. *Disability and rehabilitation*, *32*(4), 273-281.

Sutter-Leve, R., Passint, E., Ness, D., & Rindflesch, A. (2021). The caregiver experience after stroke in a COVID-19 environment: a qualitative study in inpatient rehabilitation. *Journal of Neurologic Physical Therapy*, *45*(1), 14.

Tsai, P. C., Yip, P. K., Tai, J. J., & Lou, M. F. (2015). Needs of family caregivers of stroke patients: a longitudinal study of caregivers' perspectives. *Patient preference and adherence*, *9*, 449.

Zeng, C., Cao, W., Zhao, T., Li, L., & Hou, L. (2021). Hope level and associated factors among parents of retinoblastoma patients during COVID-19 pandemic: a cross-sectional study. *BMC psychiatry*, *21*(1), 1-10.