

## A REVIEW ON PSYCHOSOCIAL SUPPORT AMONG CAREGIVERS OF STROKE SURVIVOR

Umami Mirza Baharudin<sup>1</sup>, Azarrudin Hussin<sup>1</sup>, Faiz Daud<sup>1</sup>

<sup>1</sup>Department of Community Health, Faculty of Medicine, The National University of Malaysia

\*Corresponding author: Faiz Daud, Department of Community Health, Faculty of Medicine, The National University of Malaysia. [faizdaud@ppukm.ukm.edu.my](mailto:faizdaud@ppukm.ukm.edu.my)

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### ABSTRACT

**Background:** Stroke mainly affect individuals at the peak of their productive life. Caring for stroke survivors often puts a considerable burden on the caregivers. This review is aimed to show the importance of support systems to caregivers in caring the stroke survivors.

**Materials and Methods:** Literatures were gathered from four search engine; PubMed, Web of Science, Ovid Medline and Ebscohost. Selection process was done through PRISMA process. 30 articles were selected after thorough identification, screening, eligibility process; among 3,812 articles from the search.

**Result:** Coping mechanism, perceived high social support, and self-sacrifice are domains that may give strength to the caregivers. However, the challenging domains that hit the weakest point of caregiver, that may impact negatively for both survivor and the caregiver includes loss of income, burnout, withdrawn in society, unpreparedness or unmet need, burdensome, depression, declined in quality of life (QOL) and activity or work limitation. Provision system would need to include psychological, community and financial supports besides education on caring for stroke survivor.

**Conclusion:** Findings of this review may address problems that could be converted into policy and practice. These caregivers have specific needs that could be tackled by health authorities and healthcare professionals.

**Keywords:** Stroke survivor, caregiver, support systems.

## 1.0 Introduction

Global prevalence of stroke worldwide in 2017 was 104.2 million people, whereas that of ischemic stroke was 82.4 million, that of intracerebral haemorrhage was 17.9 million, and that of subarachnoid haemorrhage was 9.3 million. Apart from this values, 6.1 million individuals died of stroke, as reported by American Heart Association (Virani SS, S, Lackland DT, Mussolino ME, & Spartano NL, 2020). Strokes mainly affect individuals at the peak of their productive life. Despite its enormous impact on countries' socio-economic development, this growing crisis has received very little attention to date.

Stroke is defined as sudden death of brain cells due to lack of oxygen, caused by blockage of blood flow or rupture of an artery to the brain. It is considered as second leading cause of death, and third leading cause of disabilities world widely. The stroke survivors are the stroke patient who has permanent impairment post-stroke event. The impairment or disability that possibly occurred are; paralysis or problems controlling movement, such as walking or balance and/or swallowing, sensory (ability to feel touch, pain, temperature, or position) disturbances, difficulty using or understanding language, thinking and memory problems, or emotional disturbances (Department of Neurology, 2015).

Caregiver as defined in Oxford dictionary; is a person who are takes care of a sick person or elderly (Dictionary., 2020). Family members, close relatives, friends, or neighbour who are not trained to be formal nursing/health professional, but care for the stroke survivor at home with or without paid, are termed as informal caregivers. This informal caregiver of stroke survivor might experience challenges and difficulties during taking care their stroke survivor. Due to abrupt onset of disability, chronic, often unpredictable and non-prepared; caring for stroke survivors often puts a considerable burden on the caregivers, especially for 6 months episode post-stroke event. Caregivers may experience changes life in many ways. Numerous researches were done to see the life impact of being the caregivers of stroke survivor. Most studies conclude that caregivers need some sort of comfort and support. Failing to fulfil the support systems may affect the caregivers' mental health (Han et al. 2017). There is various study conducted to see the detrimental impact of caring stroke survivors. This review aimed to show the importance of support systems to caregivers in caring the stroke survivors.

## 2.0 Materials and Methods

### 2.1. Literature Research

A structured and systematic electronic search was conducted using 4 major search engines; PubMed, Web of Science, OvidMedline and Ebscohost. The articles were published between 2010 and 2020. The literature search was conducted using specific keywords and identified Medical Subject Heading (MeSH) terms for PubMed. The PICO search strategy was used, and keywords used are shown in Table 1.

Table 1. Search strategy and keywords

PROBLEM	COMPARISON	OUTCOME
Strokes	Caregiver	Psychosocial Support System
Cerebrovascular Accident	Carers	Support System, Psychosocial
Cerebrovascular Accidents	Carer	Financial Support
CVA (Cerebrovascular Accident)	Care Givers	Social Support System
CVAs (Cerebrovascular Accident)	Care Giver	Social Support Systems
Cerebrovascular Apoplexy	Spouse Caregivers	Support System, Social
Brain Vascular Accident	Caregiver, Spouse	Support Systems, Social
Brain Vascular Accidents	Caregivers, Spouse	System, Social Support
Cerebrovascular Stroke	Spouse Caregiver	Systems, Social Support
Cerebrovascular Strokes	Family Caregivers	Psychological Support System
Stroke, Cerebrovascular	Caregiver, Family	Psychological Support Systems
Apoplexy	Caregivers, Family	Support System, Psychological
Cerebral Stroke	Family Caregiver	Support Systems, Psychological
Cerebral Strokes		System, Psychological Support
Acute Stroke		Systems, Psychological Support
Acute Strokes		
Acute Cerebrovascular Accident		

Several inclusion and exclusion criteria were applied in the literature search. The inclusion criteria include articles within 10 years in 2010 and 2020, open access, English language, full text applicable, studies that elicited the support towards the topic of this review. Exclusion criteria of the search include non-human studies, non-stroke studies, and studies on child with disabilities.

## 2.2. Quality Assessment

Studies were evaluated for methodological quality using standard quality assessment criteria for evaluating primary research papers from various field's checklist. The checklist has been considered as appropriate tools to value the quality of qualitative studies. 10 criteria were used to evaluate the quality of the study, which included (1) study objective, (2) study design, (3) study context, (4) connection to a theoretical framework, (5) sampling strategy, (6) data collection, (7) findings analysis, (8) use of appropriate tools, (9) conclusion, and (10) account reflexivity. The score was obtained depending on the degree to which the specific criteria were met. ('yes' =2, 'partial' = 1, 'no' = 0). The summary score for each study was subsequently calculated by summing the number and was timed up 100 to get in percentage. Articles with >75% will be selected for review.

## 2.3 Data Extraction

Two authors independently extracted the information from the relevant articles. Title of the articles was screened, based on inclusion and exclusion criteria. Then, those abstracts deemed relevant were retrieved and screened again, based on the criteria. Workflow process of articles selection were summarized in Figure 1. Selection process was done using PISMA flow diagram.

Duplicated articles were removed using End Notes software. Information study design, tools, intervention of the study, reported finding and type of support systems were summarised in an extraction table. Data were compared and was discussed to reach a final consensus.

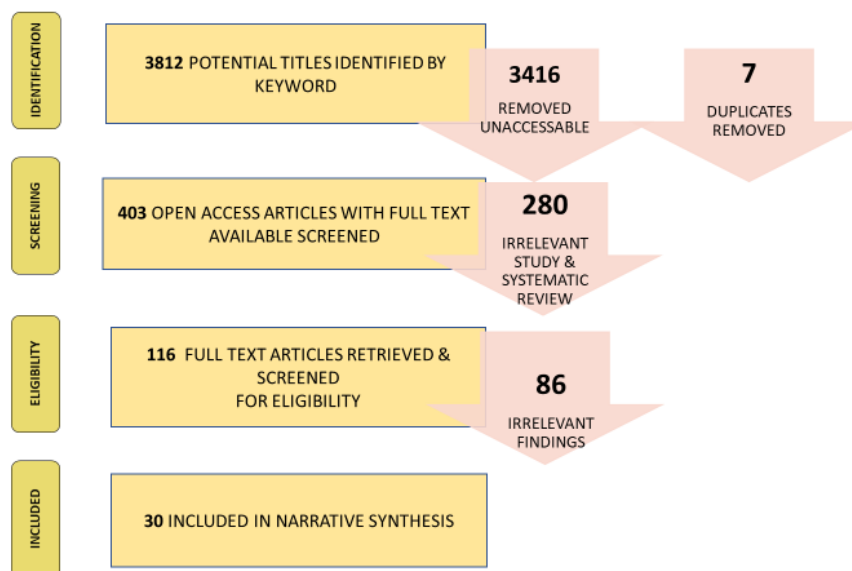


Figure 1. PRISMA flow process

Table 2. Results of 30 relevant articles related to support systems.

No	Author	Year	Sample size	Study design	Tools	Findings
1	Wagachchige et al	2018	10	A qualitative exploratory research approach	In-depth interviews	Loss of income either of the stroke survivor or of the caregiver was a major reason for financial problems.
2	Xia X et al	2019	1119	Cross-sectional	National institutes of Health Stroke Scale (NIHSS) score, WSO	Psychological support (93.5%), treatment and care(88.6%), information (84.8%) and social support (62.7%).
3	Juan Oliva-Moreno et al	2017	406	Observational, prospective, multi-centre study	Self-administered 22-item questionnaire	Likelihood of being at a high risk of burnout was 1.78 times higher (4.33 times higher at 12 months poststroke) when the caregiver provided >10 hours of care per day.
4	Qi Lu et al	2018	26 family caregivers	Explorative design	Interview	Caregiving affected them physically, psychologically, and socially to such a degree that they were living on the edge of what they were able to manage
5	Jessica L. McCurley et al	2019	24	Explorative design	Interview and focus group questions	The challenges and impacts of stroke most commonly reported by dyads were uncertainty about future health, fear of recurrent strokes, negative emotions, and role changes post-stroke
6	Alexandra M. J. Denham et al	2019	24	Explorative design	Semi-structured phone interviews	Carers of stroke survivors desired the development of services which provide connectivity to information, training, education and community support and inclusion in a community with social relationships and other carers of stroke survivors.
7	Michelle Camicia et al	2018	12	Exploratory triangulation design	Interview	Descriptive statistical analysis of the Family Inventory of Needs revealed that both met and unmet needs were consistent with the interviews and the interpretations of the drawings
8	Marivic B. Torregosa et al	2017	11 survivors, 8 caregivers	Qualitative exploratory research design	IRB-approved interview guide	Life was the overarching theme of stroke survivors' and caregivers' post-stroke recovery and readjustment journey

9	Olivia Xichenhui	2017	25 family caregivers	Qualitative descriptive design	Semi-structured interviews	(1) Caregiving role perception. Informants accepted caregiving for the sick family member as an expected part of life, a culturally prescribed obligation, and an expression of reciprocal love. (2) Coping strategies. Connecting with family resources and connecting with inner strength were frequently reported coping strategies. (3) Self-sacrifice.
10	Emmanuel Chiebuka Okoye	2019	82	Cross-sectional survey	Caregivers Strain Index (CSI), the Igbo-culture adapted Maleka Stroke Community Reintegration Measure (MSCRIM)	80.5% of the caregivers experienced significant burden
11	Wei Zhu et al	2018	202	Prospective longitudinal study	Face to face or telephone interview	Caregiver burden decreased from T1 to T3 significantly. The physical function, depression of stroke survivors, and self-rated burden of caregivers were the most important determinants for overall caregiver burden. The factors identified explained 41.6% to 67.4% of overall burden
12	Yu-Hsia Tsai et al	2018	126	Cross-sectional study	Questionnaire	Higher caregiver burdens, lower caregiver education level, lower self-rated health, lower monthly family income, and spouses who were responsible for medical fees were significant predictors of lower caregiver QoL.
13	Enkhzaya Chuluunbaatar et al	2017	103	Prospective, multi-centered observational study	Self-administered questionnaire	Approximately 8% of the caregivers reported that they had poor health, and 56% of them reported that they had faced financial difficulties, whereas 30% of them reported that they had always or usually faced financial difficulties.
14	Ngo X. Long et al	2018	126	Cross-sectional study	Demographic questionnaire	Nurses should take care-giver's age, functional status of stroke survivors, caregiver burden, and social support into consideration when preparing family caregivers to provide care for stroke survivors
15	Fidel Lo'pez-Espuela et al	2018	67	Qualitative study	Individual, semi-structured, in-depth interviews	Loss of independence, autonomy and ability to plan daily living, normal patterns and relationships as well as the loss of certainty about stroke event and its consequences in a medium-long term and the loss of self confidence in coping with this, result in spouses' negative psychological experiences

16	Yanhong Han et al	2017	328	Prospective longitudinal study	Short Portable Mental Status Questionnaire, Multidimensional Scale of Perceived Social Support, Caregiver Strain Index	Of the 209 dyads recruited, 164 completed all data collection phases, with 69% of the female caregivers aged 56.04 (SD = 4.0; range = 22-80) years. Caregivers reported higher mean burden at T1 (7.35 + 2.9) but slightly decreased over time at T4 (6.34 + 3.4), had borderline mean depressive symptoms only in T1 (9.71 + 3.2) and T2 (9.02 + 3.8), and had moderate mean social support throughout the 6-month period.
17	Yueqin Pan et al	2015	126	Cross-sectional correlational design	Structured questionnaires	Caregivers mutuality, education, full employment or being retired, monthly income, having a co-carer, and having a father as the care receiver were significantly positively associated with caregivers perceived social support
18	Enkhzaya Chuluunbaatar et al	2015	155	Multicenter prospective study	World Health Organization QoL-BREF questionnaire	Among the caregivers, these factors were poor physical health ( $\beta = -9.11$ , $p = 0.013$ ) and financial difficulties ( $\beta = -9.73$ , $p = 0.008$ ).
19	Jaracz K, et al.	2014	88	Cohort	Caregiver Burden scale, Hospital Anxiety and Depression scale, Berlin Perceived Social Support Scale	Depression: 16% Anxiety 22 to 26% Unsatisfied in life 57% to 51%
20	McLenno S.M. et al.	2014	242	Descriptive analysis	Oberst Caregiving Burden Scale (OCBS) for perceived task difficulty.	Non-spouse caregivers (52%), 47% reported mild to severe depressive
21	Creasy Kret al	2013	17	Cross sectional	In-depth interview	Caregiver demand full attention and concern from health care provider in terms of emotional support need
22	Ganapathy V et al	2015	153	Cross sectional	(Oberst Caregiver Burden Scale), Work Productivity and Activity Impairment	Perceived time spent (46.1) than difficulty (32.4), activity limitation Among employed caregivers (n=71) due to absenteeism, presenteeism, work limitation.
23	Malini H.	2014	240	Case-control. True experimental pre-test and post-test design	Intervention	Self-help group participant achieved higher score of family system strength compared to those control group. 39.45% (37.6–41.28%)
24	Marima P, et al.	2019	71	Cross-sectional	Shona Symptoms Questionnaire (SSQ) was used to measure psychiatric morbidity.	Caregivers who received an adequate amount of social support were likely to report of lower psychiatric morbidity ( $Rho = -0.285$ , $p = 0.016$ ). More 80% of carers reported of inadequate finances

25	Lui MH, Lee DT, Greenwood N, Ross FM.	2011	103	Prospective, longitudinal	Instrument for caregiver: Hospital Anxiety and Depression Scale (HADS), Health Survey Short Form 36 (SF-36), Medical Outcome Study Social Support Scale (MOS-SSS) , Social Problem-solving Inventory (PSI),	Anxiety and depression that showed significant reductions (p =0.02 anxiety and p =0.004 depression). Improvement in survivors' functional independence level t = 22.7, p =0.001
26	Cecil Ret al	2012	30	Qualitative descriptive study	In-depth interview	Framework composed of (1) the impact of the stroke event on the carer; (2) the extrinsic factors that support the caring scenario; and (3) the intrinsic factors that help a carer to cope with the new role. Changes to lifestyle, Health professionals, Own health and well-being, Concerns and worries, Information and knowledge, Gratitude and faith, Mental health issues, Family support, The dyadic relationship
27	King RB et al	2012	255	Randomized control trial	CPSI consisted of a manualized 10-session intervention	Moderate to severe depression (CES-D > 30) was found in 28% at baseline and 10% at T4. A total of 89 caregivers were referred for counselling for scores 30. No significant difference was found in referrals by group
28	King RB et al	2010	58	Longitudinal, mixed methods descriptive design	Problem-solving coping was measured using the Social Problem-Solving Inventory Revised short form.	3.71 (SD = 1.01; fairly stressful) for stroke survivor functioning. Caregivers were less effective in managing interpersonal disruptions (M = 2.64, SD = 1.12; a little effective) compared with survivor functioning (M = 3.60, SD = 1.15; fairly effective) and sustaining the self and the family (M = 3.85, SD = 1.22; fairly effective).
29	Lopez-Espuela et al.	2017	18	Phenomenological research	Semi-structured, in-depth interview	Spouses who care for a partner after a stroke are also intensely altered. This alteration results in a loss of earlier life—as reflected in the expressions of losing the life that once was and lives turned upside-down
30	Ali, Nayab et al	2016	90	Cross-sectional	Multidimensional Scale of Perceived Social Support (MSPSS) used to measure social support perceived by caregivers of stroke patients,	Caregivers tried to go through their difficult time by indulging themselves in religious activities and rituals more than usual. Caregivers also using more avoidance coping by withdrawing from others.



### 3.0 Result

#### 3.1 Characteristics of the articles

A total of 30 articles were finally selected and considered for review. Overall, there were 5 articles published most recent in 2019, and the only one oldest article was published in 2010. All studies were qualitative studies, and was conducted in 14 country; Sri Lanka, China, US, Australia, Mongolia, Spain, UK, Poland, Zimbabwe, Nigeria, Vietnam, India, and Pakistan. Overall, the 30 appraised articles about 13 articles was scored 100% whilst 17 articles were scored between 75 % to 99%. Caregivers demographic features are informal caregiver, most of them are female, aged more 18 years old, considered healthy and fit, spouse or children of stroke survivor, un-aid care, providing care to the stroke survivor, and stayed together with the patient.

#### 3.2 Three major components of the reviewed articles

We have divided the outcome of this review into 3 major components:

##### 3.2.1 Positiveness attributes of the caregivers

From this review, there are 3 positiveness variables we could captured. 3 articles have mentioned about good coping mechanism, 2 articles perceived good social support while handling the stroke survivor, and 1 article mentioned self-sacrifice that made the caregivers even stronger.

A study showed cultural and religious backgrounds were found to influence Chinese stroke caregivers' experience, coping strategies, and self-sacrifice behaviour in idiosyncratic ways. There are 3 ways to describe this coping mechanism. (1) Caregiving role perception. Informants accepted caregiving for the sick family member as an expected part of life, a culturally prescribed obligation, and an expression of reciprocal love. (2) Coping strategies. Connecting with family resources and connecting with inner strength were frequently reported coping strategies. (3) Self-sacrifice (Xichenhui., 2017). Various factors were found to play their part in affecting how the carer copes with his or her new role. Knowledge of these factors, characterized here as intrinsic and extrinsic, will help nurses and other health professionals to identify pockets of need and enable them to focus their supportive interventions quickly and appropriately (Cecil, Thompson, Parahoo, & McCaughan, 2013). There is the need to support caregivers during the transition to home care. Life disruptions occur instantly and result in multiple problems with a range of stressfulness and coping effectiveness that can result in chronic stress (King, Ainsworth, Ronen, & Hartke, 2010).

Lui et al stated that caregiver self-appraised problem-solving abilities (PSI) were predictive of later perceptions of social support. Confidence in problem-solving (PSC) and personal control over emotion and behaviour during problem-solving (PC) were significant predictors of physical well-being (PWB) and the extent to which caregivers perceived elements of caregiving as difficult (CAS). Caregivers mutuality, education, full employment or being retired, monthly income, having a co-carer, and having a father as the care receiver were significantly positively associated with caregivers perceived social support (Pan & Jones, 2017).

### 3.2.2 Weakest among caregivers while caring a stroke survivor

There are 9 variables described the weakest point of caregivers while caring stroke survivors. 4 articles had mentioned loss of income or financial constrain, 3 articles highlight about depressive caregiver, 2 articles mentioned how burden the caregiver are and decline in quality of life. Other variables like burnout, withdrawn in society, unpreparedness or unmet need, decline in marital relationship, activity and work limitation; they revealed one each.

Study showed approximately 8% of the caregivers reported that they had poor health, and 56% of them reported that they had faced financial difficulties, whereas 30% of them reported that they had always or usually faced financial difficulties (Chuluunbaatar, Pu, & Chou, 2017). A significant negative relationship is found between family monthly income and psychological distress that is, anxiety, depression and stress. The relationship of caregivers' social support by significant others and friends is found to be positively correlated with family monthly income of caregivers (Ali & Kausar, 2016). Financial support was also needed by stroke survivors to maintain their treatment, care and activities of daily life.<sup>15</sup> Social security systems for stroke survivors need to be improved in developing countries (Xia et al., 2019)

Caregivers' burden remains a serious problem in the first six months. It is an increasing hazard, especially for those at an advanced age who have depressive symptoms and care for severely dependent stroke survivors requiring more caring hours (Han et al., 2017). Caregivers need to be informed early that feelings of stress may vary over a considerable period of time and warrant attention throughout the first year of stroke recovery. White race and less than high school education contribute to negative outcomes for family functioning, and anxiety, respectively, can alert clinicians to potential adaptation issues (King et al., 2012) Stroke caregivers with depressive symptoms may experience greater task difficulty and more negative life changes during the initial period (McLennon, Bakas, Jessup, Habermann, & Weaver, 2014).

80.5% of the caregivers experienced significant burden (Okoye et al., 2019). Higher caregiver burdens, lower caregiver education level, lower self-rated health, lower monthly family income, and spouses who were responsible for medical fees were significant predictors of lower caregiver QOL (Tsai et al., 2018).

Spouses who were responsible for medical fees and lower monthly family income had direct negative effects on caregiver QOL (Tsai et al., 2018). There is a need for greater attention to be paid to the needs of caregivers as their poor well-being can translate to poor survivors' well-being (Okoye et al. 2019).

Likelihood of being at a high risk of burnout was 1.78 times higher (4.33 times higher at 12 months poststroke) when the caregiver provided >10 hours of care per day. Therefore, changes of caregiving time in each activity may devoted the burnout throughout 1-year follow-up. A helps to identify indicators that can predict the burden of caregivers and the risk of burnout is mandatory (Oliva-Moreno et al., 2018).

Caregiving affected the caregiver physically, psychologically, and socially to such a degree that they were living on the edge of what they were able to manage. Therefore, healthcare authorities and professionals should recognise and understand the life situation of family caregivers after their relative has experienced a stroke in order to identify their difficulties and needs. Offering and implementing appropriate and effective support, such as peer support, economic support

and household or volunteer services, for family caregivers should be prioritised (Lu, Mårtensson, Zhao, & Johansson, 2019).

Addressing met and unmet need of stroke survivors and their caregivers prior to discharged from rehabilitation unit is important. It may enhance communication, support, and effective caregiver education amidst the crisis of stroke. Therefore, authorities need to provide a family-centered environment where the needs of family caregivers at the bedside of stroke patients are addressed and preparation for the transition to the caregiving role following discharge is optimized (Camicia, Lutz, Markoff, & Catlin, 2019).

Caregivers experienced a high cost in productivity as measured by absenteeism, presenteeism, work productivity, and activity limitation. Employed caregivers should be encouraged to consider Family Medical Leave Act provisions for unpaid leave, and seek professional help to bolster retirement savings and investments (Ganapathy et al., 2015).

### **3.2.3 Demands from caregivers for support systems**

Five variables were derived described the demand of caregivers in terms of support systems. 5 articles have mentioned a need for supportive group, 4 articles mentioned about social support, 3 articles highlight about burden to be decreased by period of time, and 2 articles for each variable of psychological and informative support.

Caregivers who received an adequate amount of social support were likely to report of lower psychiatric morbidity ( $Rho = -0.285$ ,  $p = 0.016$ ) (Marima, Gunduza, Machando, & Dambi, 2019). Some respondent felt lack of support from health care provider, lack of being listened that led to frustration and dissatisfaction of care (Creasy, Lutz, Young, Ford, & Martz, 2013). In order to reduce perceived caregiver burden, family support interventions should be embraced to enhance health status of the caregivers of stroke survivors (Long, Pinyopasakul, Pongthavornkamol, & Panitrat, 2019). Therefore, support group intervention programmes provided to the caregivers had a significant impact on their family system strengths (Malini, 2015).

Jaracz et al revealed that low social support at 6 months low support after 5 years may resulted depression, anxiety and unsatisfied in caregiver's life (Jaracz et al., 2015). The challenges and impacts of stroke most commonly reported by dyads were uncertainty about future health, fear of recurrent strokes, negative emotions, and role changes post-stroke. Hence, supportive social networks encompassed all the people extended a helping hand to the caregivers willingly (Wagachchige Muthucumarana, Samarasinghe, & Elgán, 2018). There is a suggestion to provide a first step toward the development of feasible, accessible, and patient-centered interventions for at-risk stroke survivors and their caregivers aimed at preventing chronic psychiatric illness in both members of the dyad (McCurley et al., 2019). Psychological distress experienced by the caregivers of stroke patients can be reduced by providing greater social support. Family monthly income also plays a vital role in psychological distress experienced by the family caregivers (Ali & Kausar, 2016).

Caregivers was reported higher mean burden but slightly decreased over time, had borderline mean depressive symptoms only and had moderate mean social support throughout the 6-month period. More professional caregivers are needed to support informal carers (Han et al., 2017; Zhu & Jiang, 2019).

A study showed that the QOL of the of stroke patients in the physical health and environment domains significantly improved after 1 year; however, QOL of the caregiver's in the social relationship and psychological health domains was declined (Chuluunbaatar, Chou, & Pu, 2016). Psychological distress experienced by the caregivers of stroke patients can be reduced by providing greater social support. Family monthly income also plays a vital role in psychological distress experienced by the family caregivers (Ali & Kausar, 2016).

Various factors were found to play their part in affecting how the carer copes with his or her new role. Knowledge of these factors, characterized here as intrinsic and extrinsic, will help nurses and other health professionals to identify pockets of need and enable them to focus their supportive interventions quickly and appropriately (Cecil et al., 2013). Carers of stroke survivors desired the development of services which provide connectivity to information, training, education and community support, and inclusion in a community with social relationships and other carers of stroke survivors (Denham et al., 2019).

#### 4.0 Discussion

The high number of women caregivers in almost literature, where caregiving is considered as a woman's role even if she has fulltime employment. Various factors were found to play their part in affecting how the carer copes with his or her new role. Knowledge of these factors, characterized here as intrinsic and extrinsic, will help nurses and other health professionals to identify pockets of need and enable them to focus their supportive interventions quickly and appropriately (Cecil et al. 2013).

Consistent with most literature, the high levels of stress and burden of caregiving made it difficult to find balance between caregiving, family, job and personal life. These responsibilities were so challenging and stressful often described as physical tiredness, poor sleep and body pain. The tiredness and fatigue reported by caregivers have been documented in most studies. In contrast, because of the accessible social support systems, caregivers in Japan were less stressed and had a lower sense of care burden (Morimoto et al. 2003). Perhaps, because there are currently no rehabilitation support services in certain communities, this could have had an impact on the endless stress in these caregivers. This finding gives interesting opportunities for mediation by healthcare professionals. There is need for strong institutional and professional support for caregivers of stroke patients in every country to reduce their caregiver burden.

The requirement for information support, skills and active listening to caregivers' apprehensions to feel confident about caregiving was very vital. This is consistent with the results of a systematic review which revealed the educational needs of caregivers (Creasy et al. 2013). It is possible that sometimes healthcare professionals give information only after a caregiver has asked for it. However, the help they received from the family and friends was very well appreciated by these caregivers, as other investigators have also found the same situation. Because these caregivers suffered a lot of difficulties in care, the family and friends were an essential source of support. These family relationships and support reflect the traditional extended family function (Wagachchige Muthucumarana et al. 2018). In almost supportive society and culture, the joint family support system helps in dividing the burden and supporting relatives together to enhance the patient's health care.

Consistent with many studies, the relief after the patient's recovery is an aspect of positive caregiving. The apparent benefit in the recovery of the patient allowed these caregivers to dedicate less time to providing care (Lopez-Espuela et al. 2018). Some literature has reported that even a slight physical improvement in stroke patients makes caregivers feel relieved (Farayi Kaseke 2019). For many people, grief is one of the toughest things that they will have to go across. Significantly, it can be helpful for the grieving caregivers to speak to a qualified professional about their emotions for appropriate counselling. A positive problem-solving appraisal may motivate family caregivers to have more positive expectations and thus be more willing to seek help and support from others (Lui et al. 2012). Support group intervention programmes provided to the caregivers had a significant impact on their family system strengths (Malini 2015).

Our findings address problems that could be converted into policy and practice. These caregivers have specific needs that could be tackled by health authorities and healthcare professionals. A variable and concerned mindset among health professionals which can have a positive effect on caregivers is crucial in care and has been documented (Camicia et al. 2019; Denham et al. 2019). Caregivers emphasized the need for training in the basic skills of managing a stroke patient, simple nursing tasks, information support and post discharge follow-up which can lessen the burden of care (Denham et al. 2019). Thirdly, the caregivers voiced the need for government to extend funding to them and their stroke patients with medicines, gloves and wheelchairs especially those who are disadvantaged in communities (Lu et al. 2019).

## 5.0 Conclusion and recommendation

In conclusion, caregivers suffered life changes due to sudden assumption of new responsibilities. These caregivers experienced caregiving responsibility mainly due to financial problems, emotional distress, high caregiving requirements and a lack of rehabilitation support services in their communities. With the absence of community rehabilitation assistance services, most caregivers faced constant stress in their caregiving roles which had a great influence on their lives. Many caregivers experienced an absence of information support and skills and effective listening to their concerns which were important during their caregiving tasks. Combining these multiple concerns and needs recommended by several caregivers and highlight that it is very important to support these caregivers as they care for their loved ones either at home or at health facilities to enhance the health outcomes for both the stroke patient and caregiver. All these areas can be focused to by the relevant health professionals and policy makers.

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## Declaration

Author(s) declare that there is no conflict of interest.



## Authors contribution

Author 1: Methodology, Software, Validation, Formal analysis, Original draft preparation, Editing

Author 2: Formal analysis, Writing, Resources

Author 3: Supervision, Methodology, Conceptualization

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