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## LITERATURE REVIEW ARTICLE

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### **Burdens of Family Caregivers of Stroke Patients: An Integrative Literature Review**

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#### ABSTRACT

Stroke is primarily one of the chronic diseases resulting to varying physical disabilities and cognitive changes that need assistance from the unprepared informal family caregivers. The objective of this article is to explore the burdens of family caregivers of stroke patients. This integrative review of literature from the year 2013 to 2017 using CINAHL, Medline, ProQuest and Google Scholar databases resulted to inclusion of six quantitative and two qualitative studies. Results revealed varying degrees of physical, emotional, social and financial burdens that has mostly affected the caregivers' quality of life specifically the physical domain due to various patient and caregiver related factors. Problem solving strategies to cope the consequences of burdens was commonly used. In conclusion, burdens can be curtailed if caregivers' needs will be targeted by providing stroke-related health information, training to develop care-taking skills and technique along with provision of financial, social and emotional support.

**Keywords:** Stroke, Family, Caregiver, Burden, Strain

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#### INTRODUCTION

Stroke remains to be one of the major chronic diseases worldwide that brings enormous devastating consequences. Considerable improvement has been made in primary prevention and treatment of stroke; however, it remained to be a major global health problem. In the United States of America alone, stroke is the third leading cause of death resulting to approximately 130,000 deaths annually according to Linton.<sup>(1)</sup> Similarly, stroke in the Philippines' is now the second leading cause of death in which 70% comprises ischemic stroke and 30% for hemorrhagic stroke.<sup>(2)</sup>

Despite advancement in treatment and care, patients with stroke suffer varying degrees of long term or even lifelong disability requiring caregiver assistance of which care is provided by family members. Family or informal caregiver is typically an unpaid individual who lives with the patient who can be a spouse, child, sibling, a close friend or even a neighbor who is closely involved in the care and provision of broad range of assistance with no previous training<sup>(3)</sup> contrary to the formal caregivers who are paid health aides and health professionals.

Since the onset of stroke is sudden, the patient and the family caregivers are left unequipped to manage the disability and its consequences resulting to physical, social, financial and psychological burdens.<sup>(4)</sup> Literature has documented a number of family caregiving burdens brought about by incapacity, functional limitations in mobility and communication, behavioral and cognitive changes that leads to dependency to the caregivers resulting to constant anxiety, lost social activities, stress, depression and physical exhaustion related to taxing responsibilities.<sup>(5)</sup>

Family caregiving is a burdensome role that has all of the hallmarks of a chronic stress experience in which the theory of stress, appraisal and coping is a suitable underlying assertion for recognizing the burden of family caregivers much more when these caregivers perceived that caregiving demands are taxing and exceeds the available resources a caregiver can mobilize.<sup>(6)</sup>

Family caregivers are silent clients that primarily bear the brunt of tremendous effect of long term caregiving experiences. Therefore, careful attention and understanding on the burdens faced by family caregivers are essential in order to address the burgeoning consequences. Hence, the purpose of this article is to explore the burdens of family caregivers of stroke patients. In the context of providing an organized framework regarding burdens in caregiving, this paper will address and answer: What has been published regarding burdens of family caregivers? Thus, a comprehensive search of literature was conducted.

**METHODS**

**Search Strategy**

A comprehensive review of three electronic databases, the Cumulative Index to Nursing and Allied Health Literature (CINAHL) that yielded 1,444 studies, Medical Literature Online (MEDLINE) 13 studies, Proquest resulted to 4,709 studies and one search engine, the Google Scholar that yielded 6,220 studies was conducted to identify published literature regarding burdens of family caregivers of stroke patients from August to September 2017. This literature review used the following combination of terms: ‘burden’, ‘family caregiver’, ‘informal caregiver’, ‘strains’, and ‘stroke’ to search for prospective literature. Among the studies from different databases the search yielded a total of 125 potential and relevant papers that were reviewed. Out of 125 studies, 25 studies were excluded after removal of duplicate literature and 100 studies were retrieved for examination review. After which 59 studies were excluded because one was an unpublished article, one is a non-English article and the rest were not available in full text articles. The remaining 41 articles were reviewed for methodological quality in which 33 studies were excluded after critical appraisal. Hence, after careful examination and evaluation, only eight research articles that met the inclusion criteria were included in which most of the researchers were nurses and medical doctors.

**Inclusion-Exclusion Criteria**

The inclusion criteria were limited to published, full text paper from journals in the past five years from 2013-2017 to ensure relevant and up to date literature's and in English language. A family caregiver must be a member of the family of the stroke patient, 18 years old and above and has cared for the stroke patient for at least one month. Caregivers who are not members of the family, paid, professional caregivers; and resources that did not address issues related to burdens of caregivers were excluded.

**RESULTS**

**What Has Been Published Regarding Burdens of Family Caregivers?**

**Characteristics of Selected Studies**

Table 1 provides the summary of sources included in this review of which two were carried out in Punjab-India, one was conducted in Taiwan, Peru, Mongolia, Brazil, and Thailand; while the other one did not indicate the location where the research was conducted. Based on the result of this integrative literature review, 75% of studies used quantitative methods and 25% used qualitative methods to measure and explore on the burdens of the family caregivers.

Table 1. List of sources included in review and description of studies

Author	Jaracz, Jaracz, Gorna, & Moczko <sup>(7)</sup>
Purpose	<ul style="list-style-type: none"> <li>➤ Assess the prevalence of considerable burden among caregivers of stroke survivors at 6 months and 5 years after stroke</li> <li>➤ To analyse burden severity over time and to identify factors associated with the burden</li> </ul>
Design/Sample	➤ Quantitative/ 88
Summary of findings	<ul style="list-style-type: none"> <li>➤ A significant proportion of the caregivers experienced considerable burden reported at 44% at Time 1 and declined overtime to 30% at Time 2.</li> <li>➤ Sense of coherence, time spent in caring and anxiety were the factors most related to burden at T1</li> <li>➤ Time spent in caregiving, anxiety and patients disability were the factors most related to burden at T2</li> </ul>
Author	Caro, Mendez, Costa, Nock, & daCruz <sup>(8)</sup>
Purpose	➤ Investigate whether a correlation existed between the levels of independence and cognition in stroke patients and the burden and quality of life of their caregivers

	➤ Assess whether periods of injury, rehabilitation and care, and age of stroke patients interfered with these correlations
Design/Sample	➤ Quantitative/ 30
Summary of Findings	➤ WHOQoL-BREF was 62% indicating an average quality of life
Major Findings	➤ Inverse correlation was found between burden and quality of life of family caregivers
	➤ ZBIS showed the average of 29.6 or moderate levels of burden
Author	Limpawattana, Intarasattaku, Chindaprasirt, & Tiamkao <sup>(9)</sup>
Purpose	➤ Determine the prevalence of caregiver burden based on Zarit Burden Inventory (ZBI) scores among caregivers of older persons with stroke.
	➤ Identify factors associated with higher levels of caregiver burden
Design/Sample	Quantitative/ 101
Summary of findings	➤ Based on the ZBI scores majority of the participants reported no caregiver burden (54.5%), followed by mild burden (34.7%), moderate burden (8.9%), and severe burden (1.9%).
	➤ Factors associated with caregiver burden based on ZBI scores revealed that numbers of basic ADL needing assistance by caregivers of patients with coexisting musculoskeletal conditions had a positive relation.
Author	Tseng, Huang, Yu & Lou <sup>(10)</sup>
Purpose	➤ To describe experiences of caregivers managing incontinence in stroke survivors
Design/Sample	Qualitative/10
Summary of Findings	➤ Chaos, hypervigilance, exhaustion and creating a new life are the four core categories that describe the experiences of family caregivers as they care and manage incontinence of stroke patients
	➤ Caregivers manage to learn to perform each care task through learning by doing, coping by adjusting their attitude to maintain mental balance.
Author	Chuluunbaatar, Pu, & Chou <sup>(11)</sup>
Purpose	To define the changes in caregiver's burden (CGB) in the first year of caregiving among the caregivers of stroke patients and to identify associated factors.
Design/Sample	Quantitative/103
Summary of findings	➤ During the acute phase 50% of the caregivers have low OB that increased to 57% after a year. Those with high OB (7%) had decreased to (3%) after a year. Among the six items in OB, amount of time a caregiver spent on self decreased from 3.21 to 2.43 and availability of time for recreational activity from 3.19 to 2.75.
	➤ During the acute stage 45% of the caregivers have low SB; however, it has increased to 55% after a year. Those with medium SB has increased from 24% to 32% after 1 year; however, those caregivers experiencing high SB decreased from 31% to 12% after a year.
	➤ At the acute stage, 57% have low DB that has decreased to 43% after 1 year. However, those with high DB have increased from 5% to 16% after a year.
	➤ Predictors of changes in caregivers burden include married, being a spouse, a sibling, financial difficulties, male gender and dependency
Author	Kumar, Kaur & Reddemma <sup>(12)</sup>
Purpose	➤ To identify needs, burden, coping and health related quality of life in the caregivers of survivors of stroke at selected community settings
Design/Sample	➤ Quantitative/22
Summary of findings	➤ Health information related needs were most important needs followed by seeking professional support and the need of having community support
	➤ Higher level of financial burden followed by burden in term of disturbed relationship.
	➤ The most frequently used coping strategy is acceptance, followed by problem solving.
Author	Pesantes, Brandt, Ipence, Miranda & Diez-Canseco <sup>(13)</sup>
Purpose	➤ To describe the emotional impact, main stress factors, coping mechanisms, and unmet needs of individuals functioning as informal caregivers of stroke survivor
	➤ Identify elements that could inform future interventions for caregivers
Design/Sample	➤ Qualitative/12

Summary of Major Findings	<ul style="list-style-type: none"> <li>➤ Emotional suffering was the most common consequence experienced by family caregivers. Depressive symptoms include tiredness, sadness, extreme sensitivity, difficulty sleeping, lack of motivation and physical symptoms such as headaches.</li> <li>➤ Frequently mentioned stress factors were lack of independence and time to engage in social activities such as going out with friends and visiting relatives.</li> <li>➤ Half of the participants found strength and hope in their religion</li> <li>➤ Almost all participants needed to see a psychologist to improve their mental health</li> </ul>
Author	Kumar, Kaur, & Reddemma <sup>(12)</sup>
Purpose	➤ To determine the level of burden experienced by the informal caregivers of stroke survivors, and the quality of life of these caregivers, and the relationship between the level of burden of care and QoL.
Design/Sample	➤ Quantitative/ 100
Summary of Major Findings	<ul style="list-style-type: none"> <li>➤ The mean burden score was 28.36 or described as mild burden however, the pattern of burden shows that CGs experienced high burden in disturbed relationship and loss of control in life.</li> <li>➤ The QoL according to WHOQoL BREF reveals that physical domain was mostly affected at 57.64%</li> <li>➤ Caregivers quality of life was dependent on level of burden</li> </ul>

### Characteristics of the Caregivers

The characteristics of the caregivers involved gender, age, relationship to the stroke survivor, marital status, living arrangement, education, employment status, monthly income, health status and self-reported illness, and time spent in caregiving. Majority of the family caregivers were female (70.43%) while male family caregivers were found to be (29.46%). The mean age of the caregivers is (51.58). Among the caregivers, five studies reported that (36.03%) were spouses. Among the female caregivers wives accounted to (37.83%), daughters in law (28.7%), and daughters (9.1%); while (21.8%) male family caregivers were represented by sons and sons in law. Other family caregivers are relatives (17.47%), and grandchildren accounting to (15.55%).

Five studies reported that 67.78% are married while 53.7% are not married, 5.99% are widow, 4.81% are divorced and 2.97% are separated. Three studies reported that (78.30%) of the family caregivers are living with the stroke survivors. The educational status and employment status were varied among studies. One study reported that 10% of the caregivers are illiterate, (18.86%) studied up to primary education. Three studies reported that 36.24% have studied up to secondary education, 31.7% studied up to higher secondary education. One study reported 81.55% were less than college, 31.68% were on bachelor degree or higher. And two studies reported 21.07% were graduate of more than college and higher.

Family caregivers have varied employment from being a government employee, self-employed, exclusively family caregivers and home makers. Of these 42.26% are working at home while those who combine caretaking and work is (32.69%). Only two studies provided data on monthly income however, it was difficult to make an inference due to different currencies.

Among the family caregivers, (74.10%) reported a good “self-rated health” while 24.33% have poor health in which 14.85% have hypertension. Two studies showed that (65.35%) of family caregivers attended to the needs of the patient for 24 hours or round the clock, 25.35% during daytime and 9.25% for the night time and most of the caregivers have served the stroke survivor for an average of 14 months.

### Assessment of Caregivers’ Burden

In this review varied instruments were used to measure the burdens of family caregivers. Two qualitative studies utilized semi-structured questionnaires to assess the burdens of caregivers. The different instruments that measured caregiver burden are Montgomery caregiver burden scale (Montgomery CGB, n=1), Caregiver burden scale (CBS, n=1), Zarit burden interview scale (ZBIS, n= 1), Zarit burden interview schedule (ZBIS, n=2), and Zarit burden inventory-Thai version (ZBI, n=1). The different Zarit Burden instruments demonstrated an overall mild level of caregiver burden with a mean burden score of 28.52.

The Montgomery CGB is a set of 13 questions with reported Cronbach alpha of 0.7-0.94 that measures caregiver’s burden using social context approach on caregiving experiences and how caregiving responsibilities change each aspect of caregiver’s life in Objective, Stress and Demand Burdens. The CBS is a 22 items scored from 1 to 4 that measured the general strain, isolation, disappointment, emotional involvement and environment in which higher score indicate more severe burden. The ZBI scale assessed the impact of care on social, emotional, physical and financial well-being with scores ranging from 0-to 88 in which higher score indicates greater burden. The ZBI schedule was used to reflect the stresses experienced by caregivers of disabled patients with a Cronbach alpha of 0.92. Higher score in a particular domain indicates higher burden. The ZBI-Thai version reported a 0.92

Cronbach alpha. It focused on caregiver's health, psychosocial well-being, finances, social life and relationship with subscales on personal strain, privacy conflict, guilt and uncertain attitude. Total scores are interpreted as: <21= no burden, 21-40= mild burden, 41-60=moderate burden, or 61-88= severe burden.

The patterns of burden experienced by caregivers showed predominance of burden in relationship with other family and friends (45.86%) and loss of control in life (42.09%) followed by personal strain (33.39%), financial constraint (31.32%), burdens related to emotional well-being (30.12%), role strain (23.58%) and social and family life (21.52%). One study demonstrated (39.0%) prevalence of impact of burden on guilt, (30.25%) on uncertain attitude and (18.3%) on privacy conflict. Two qualitative studies demonstrated financial impact as a burden associated with the cost of nutrient supplements, diapers and other supplies and physical strain due to demanding caregiving tasks that resulted to chaos<sup>(10)</sup>; while the other study expressed that most of the caregivers suffered the consequences of emotional impact of burden such as depressive symptoms like tiredness, sadness, extreme sensitivity, lack of motivation, difficulty sleeping and suicidal ideation.<sup>(13)</sup>

One study demonstrated that 44% of the caregivers had considerable burden at Time 1 (T1) or six months after the stroke that has declined to 30% at Time 2 (T2) or after 5 years. Among the five dimensions of burden, disappointment and general strain have the highest scores of more than 2 points at both assessment times. Additionally, among the caregivers, 50% reported severe burden at T1 but have positively changed direction at T2, however; the remaining 50% still scored above the cut off point for the burden. Overall, the average caregiver burden level for general strain, disappointment and environment have significantly declined between T1 and T2.

Another study defined the changes in burdens in three domains: Firstly, Objective Burden (OB) which is the perception that caregiving restricts effort and time in meeting other family obligations that revealed 50% of the caregivers have low OB at the acute stage that increased to 57% after one year but those with high OB have decreased from 7% to 3% specifically, the amount of time spent for self and availability of time for recreational activity Secondly, stress burden (SB) which is a form of generalized negative affect showed that 45% were categorized to have low burden that subsequently increased to 55% after a year; those with moderate SB had increased from 24% to 32% after a year, however; those with high SB had decreased from 31% to 12%. Thirdly, demand burden (DB) calls for care and attention beyond what is required. Caregivers categorized to have low DB had also decreased from 57% to 43% after a year, however; those with high DB had increased from 5% to 16% after a year. Being married, being a spouse, a sibling, financial difficulties, patient's dependency and gender are predictors for the changes in caregiving burden.<sup>(11)</sup>

#### Factors Associated with Caregiver's Burden and its Impact

Caregiver burden is affected by various factors. Three studies reported that financial difficulties are strong factors contributing to the burdens. The employment status and income of the caregivers were consequently affected and interrupted because 58.33% of the family caregivers have stopped working altogether and became dependent on the financial support of other family members.<sup>(13)</sup>

Lack of information and unpreparedness to assume caregiving role was reported by one study as factors contributing to caregiver's burden.<sup>(10)</sup> Two studies reported that providing care and doing multiple tasks at once were overwhelming that resulted to nervousness, higher anxiety levels, and physical problems that lead to sleep deprivation back pains, headache and fatigue. Depressive symptoms were expressed by one third of the caregivers<sup>(13)</sup> characterized by sadness, extreme sensitivity, and lack of motivation. However; despite of the various caregiving difficulties some caregivers consider it as an opportunity to repay the love and care they received over the years.

Three studies revealed that patient's dependency to the caregivers especially those with co-existing musculoskeletal problems, bowel or urinary control problems contributed to increased amount of caretaking time, thus; perceived as overwhelming and has negatively affected the caregivers' autonomy leaving no time for themselves and other family members.<sup>(13)</sup>

The use of Antonovsky's sense of coherence to assess the inner stress coping of the caregiver reported that weak sense of coherence and anxiety are significant factors contributing to caregiver's burden at the acute stage and high anxiety levels remains to be a factor five years after the first assessment.<sup>(7)</sup> Another study reported that (66.66%) expressed that difficult caregiving role was stressful and contributes to caregiver burden.<sup>(13)</sup>

#### Caregiver's Quality of Life

The quality of life of family caregivers has been affected by various caregiving burdens and a correlation between burden and quality of life existed. The World Health Organization Quality of Life- BREF (WHOQoL-BREF) was used by four studies to measure the caregiver's quality of life in term of overall perception of health. Two studies showed that physical health domain (53.39) was mostly affected followed by environmental health (57.08) and psychological health (58.64), with the highest quality of life score on social relations at 65.68. One study documented that 53.95% were unsatisfied with their health at both T1 and T2.<sup>(7)</sup> Another study also reported

an average quality of life at 62%<sup>(8)</sup> attributed to multifactorial causes such as dependency and cognitive changes presented by the stroke survivors.

### Coping Strategy of the Caregivers

Despite of the different faces and packages of caregiving burdens family caregivers were able to maintain their psychological, emotional, physical and spiritual well-being through the use of various coping strategies. Three studies showed that 70% used problem solving to overcome caregiving burdens. Two studies reported that 67.77% used acceptance as a coping mechanism to assuage the difficulties of caregiving. Three studies demonstrated that 56.31% of the caregivers find strength and hope in religion and going to church to alleviate care burdens, 53.97% sought social support in learning skills from professional nurses and individuals with similar experience. In two studies 45.78% of the caregivers employed distraction positive, 42.56% engaged in either blaming or denial, and 24.24% used distraction negative coping strategy. Lack of training and unpreparedness generated various coping strategy in which one qualitative study demonstrated that 41% of the caregivers cope by doing relaxing activities such as cooking and watching television.<sup>(13)</sup> Other coping are reading self-help books, doing certain procedures through experiences, maintaining positive attitude and humor about the situation and avoidance of seeing caregiving as an obligation.

### Support and Perceived Needs of the Caregivers

Support is an important facet in caregiving. In this review, the Perceived Social Support Scale (PSS) was used by one study to measure the emotional and social support. Result showed that 47.7% of the caregivers expressed low social support at T1 and 38.9% at T2.<sup>(7)</sup> One study reported that caregivers had received occasional support like assistance in household activities such a cooking, cleaning and taking care of the children.<sup>(13)</sup> Three studies identified that 81.06% of the caregivers need health information on how to adequately care for the stroke survivor such as skill building, rehabilitation exercise, and prevention of a new stroke. One study demonstrated that 80.19% need professional support and seeing a psychologist to improve their mental health, 76.62% need community support network, 71.14% need instrumental support, 64.63% need emotional support and 41% expressed the need for social support. Other needs are training and educational program, more sensitive staff and more convenient centers offering physical therapy.

## DISCUSSION

The increasing incidence of stroke has greatly affected the family caregivers. On the results achieved, care is provided mostly by women family caregivers who are living with the patient and bear varying degrees of caretaking burdens. This is consistent with the findings of Sharma, Chakrabarti and Grover that women are the majority of unpaid caregivers due to gender role expectation, societal and certain cultural demands.<sup>(14)</sup> This implies that women are more likely exposed to the stressors and burdens of caregiving.

This review revealed five different instruments that measured caregiver burdens, however; taken altogether it assessed a broad range of burdens experienced by family caregivers in different levels that can be amalgamated into different aspects such as physical, emotional, financial and social burdens. Physical workload bears the highest level of burden which can be explained by dependency, disability, old age, co-existing musculoskeletal conditions of the stroke survivor and round the clock caretaking time which was supported by earlier studies.<sup>(15)</sup> Physical health is the most affected quality of life domain affecting sleep pattern leading to physical exhaustion which is consistent with the study of Berg, Palomaki, Lehtihalmes and Kaste.<sup>(16)</sup> Although in contrast, caregivers had also experienced decreased levels of objective burdens and stress burdens after a year which can be explained by the increased amount of time for caregiving chores at the beginning than that after one year and also due to physical improvement of the patient, and eventually caregivers were able to find ways to cope and adjust to the situation which is linked to adaptation theory.<sup>(17)</sup>

Financial constraint and other responsibilities can escalate to emotional distress affecting the caregiver's quality of life and psychological health which is supported by Greenwood and Mackenzie<sup>(18)</sup> that caretaking difficulties contribute to emotional burden. The suddenness of stroke leads transition to caregiving role as chaotic, stressful and overwhelming which is linked with the crisis theory according to Meleis that is why nurses and healthcare practitioners must have a clear understanding of the burdens of caregiving and its consequences.<sup>(19)</sup> Quinn et al. support that improved knowledge on caregiving tasks are protective factors against negative impact of caregiving.<sup>(3)</sup> On the other hand, financial impact is another stress factor affecting those who were compelled to stop working and became financially dependent to other members of the family. Coughlin reported that financial security due to employment and social support contribute to higher well-being and instrumental in easing the burden of the caregiving role.<sup>(20)</sup>

Taking into account the needs expressed by family caregivers, it is therefore imperative that nurses must devise a plan of care to address the needs of family caregivers by providing preparatory education on stroke-related information from admission to help increase acceptance and commitment to care and a little more time to prepare and process the mindset of the caregivers. Notwithstanding the impact and consequences of caregiving, family caregivers have adopted various coping strategy to assuage the different degrees of burdens and have displayed positive caretaking attitude as a way of paying back the patient. This explains that not all caretaking activities have negative impact but has also a positive impact on those providing care especially those who feel appreciated.<sup>(18)</sup>

## CONCLUSION

In conclusion, the unexpected occurrence of stroke drives the unprepared informal family caregivers specifically women to undertake transition into difficult and changing roles. A body of evidence showed that family caregiving is burdensome brought about by the severity of patient's physical disability, cognitive changes, dependency and even caregiver related factor such as weaker stress-coping abilities culminating in different degrees of physical, social, emotional and financial burdens. These burdens have predominantly and negatively affected the caregivers' quality of life particularly the physical health domain despite evidences that caretaking has also some positive impact to the caregivers. The inconsistent and insufficient socioeconomic and emotional support received from other family members generated problem solving strategies to cope with the burdens of caregiving. However, burdens can be curtailed if preparatory education must be imperatively planned and effected to address family caregivers need before assuming caretaking tasks along with provision of financial, emotional and social supports.

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