The Burden of Caregivers due to Stroke Patients Living at Home: Integrative Review

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Abstract

An integrative review is an internationally accepted approach that is often used for identifying, analyzing, reporting, interpreting and drawing the theme conclusions from multiple studies. This study aimed to synthesize perspectives of the burden upon stroke caregivers. Data were collected from international databases. Qualitative studies reported the perceptions of the caregivers in caring for persons who had suffered a stroke. The search was limited to the English language; journal articles; age groups included all adults; quantitative studies or irrelevant articles were excluded. Eight articles relevant to the objective were included. The identified data were extracted from the results in the eight relevant sections and then ATLAS.ti 8 Software was used for the analysis of the qualitative studies. The results of this study were synthesized into three main themes: (1) the level of the caregiver burden; (2) the environmental factors of the burden, and (3) the related illnesses from the burden. Conclusion: The integrative review of qualitative studies about the burden endured by stroke caregivers arranged unique insights into the stroke caregiver perceptions and extracted their expressions of behavior into three themes about the burden. These findings could serve as a basis for creating a program to reduce the burden of stroke caregivers.

Keywords : integrative review, qualitative study, burden, stroke caregivers

The burden was assessed from the perspective of individuals through four viewpoints: as physical, psychological, social, and financial overload. Some studies separated the burden of caregiving into two groups: the specific events or activities as an objective burden, and the emotions, feelings, and attitudes as a subjective burden.[1,2] Even though some papers stated that caregivers have positive feelings, and negative feelings can occur on many occasions, such as stress, worries, or guilt because of their responsibility to take care of patients. Moreover, the caregivers who had chronic health problems themselves increasingly experience high levels of stress and burden.[3,4]

Stroke was found to be the leading cause of long-term disability. Stroke was a traumatic life event not only for the persons who had the stroke but also for their family caregivers. Stroke patients have significantly limited functioning resulting from the disability of movement and of personal activities, impairment in cognition, and depression or change in personality. Most of the stroke caregivers carried the main responsibility for the care of the stroke patient at their home. Sometimes, they acted like parents, which caused tension in the relationship. Changes in roles, relationships, and responsibilities may induce caregiver burden. The activities, financial duties, and necessary tasks all potentially created a burden for caregivers. The achievement of balance in caregiving was important as it could influence the health and well-being of caregivers.[3,5,6]

Integrative review is a method in primary qualitative research that identifies, analyzes, and draws the themes that form conclusions from multiple studies.[7] From the literature review, several studies reflected

the negative feeling of caregivers during their care for patients. There are many feelings affecting caregivers such as stress, anxiety, depression, anger, and others. These feelings are the negative caregiving perceptions of caregivers especially in caregivers of stroke patients. The themes of the stroke caregivers' burden were broad and unclear. Using a thematic analysis can help to identify the themes about the burden of stroke caregivers from multiple studies. The screening process of the systematic literature search followed the process from Robin Whittemore and Kathleen Knaf is shown below in Table 1.

Table 1: The screening process of the systematic literature search.[8]

Stage of review	Illustration of decisions and issues
Problem identification	Data extraction from qualitative research about stroke caregivers aimed to explore and identify the burden of stroke caregivers and synthesized within themes.
Literature search	The methods used data sources accessed from qualitative studies from PubMed, CINAHL, and Cochrane showing sixty-one studies. Seven relevant articles met the inclusion criteria.
Data evaluation	The ATLAS.ti 8 Software was used to extract data and coded, categorized, and summarized the concepts about caregiver burden by theme.
Data analysis	The results are reported in two Tables. There is a synthesis identifying the findings of seven studies and the new knowledge of the phenomenon of caregiver burden.
Presentation	Conclusions of this integrative reviews were identified in a better understanding of the burden and how best to manage the burden of stroke caregivers

Qualitative research and stroke caregivers

Most of the stroke caregivers were informal carers; for example, spouses or family members.[5] They carried the main responsibility of caring for the stroke patient at their home. If the care was not balanced, it could have a negative impact upon the health and well-being of the caregivers.[3]

Qualitative research about stroke caregivers was useful for seeking in-depth information to understand the things which happen to them or the related phenomena based on a constructivist paradigm.[5] This study was an attempt to review the experiences and perceptions of stroke caregivers and to synthesize these within themes. There were several related symptoms in the qualitative studies about stroke caregivers' burden based on different cultural contexts.[9] The associated symptoms were the harmful effects on emotional well-being presenting both physical and psychological expression. This study seeked to narrow down several of the symptoms associated with the burden of stroke caregivers and to extract the codes and determine the themes.

Methods

Data sources included PubMed, CINAHL, and Cochrane. The following keywords were used in the study: "stroke or cerebrovascular accident or CVA"; "caregiver"; "burden"; "qualitative". Sixty-one studies were identified from the databases published during the period from 2007 to 2017. After duplicated studies had been removed, the following evaluation of the remaining thirty-six studies was included in this review. The abstracts of the studies were read and screened to exclude non-matching content. A fifth of the studies was excluded due to being published more than ten years earlier, using a combination of relevant Medical Subject Headings, Qualitative research or study, not an academic journal, not PDF full-text terms, and no English language. In all, the researcher read every full-text selected paper to identify ten studies. Three studies were excluded because they did not focus on stroke caregivers. The last seven relevant articles met the inclusion criteria: (a) focusing on the burden and the environmental factors that lead to the burden; (b) focus on caregivers who are caring for stroke patients, and (c) these articles came from qualitative studies.

Data were analyzed using the ATLAS.ti 8 Software and coding with line by line result findings applying grounded theory synthesis which comes from the basis of primary research. In the process, the data were extracted from the results of the seven studies. The next step then involved identifying and coding the concepts about caregiver burden listed in terms of initial codes with definitions and frequencies in the dataset. Moreover, the researcher grouped the codes and analyzed the same meanings of caregivers' feelings in the themes.

Results

Most of the studies mentioned the perceptions and experiences of caregivers who had an impact upon their quality of life. The synthesis identified the findings of the seven studies is presented in Table 2.

Coded data and themes emerging from the analysis identified by the researcher were confirmed with the theory of triangulation. All similar meaning codes were placed in groups by categories arising around themes. Three main issues emerged from the seven studies of caregiver burden: (1) level of the caregiver burden; (2) environmental factors of the burden, and (3) related illnesses from the burden.

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Table 2: Synthesis identified the findings of recurrent studies.

Stage of review	Illustration of decisions and issues	
Bastawrous M, et al. 2015 [11]	To explore experiences of daughters with and response to holding multiple roles while providing post-stroke care to a parent.	Caregivers felt role overload separated to two themes: 1) valued relationships, 2) ability to participate in valued activities.
Cao V, et al. 2012 [12]	To explore the perspectives of caregivers of stroke patients on their physical activity.	Four main themes: change in role, change in activity, barriers to activity and health, and change in the meaning of the activity. The barriers of caring included guilt, time, and energy.
Cecil R, et al. 2013 [3]	To explore caring and coping among caregivers of stroke survivors and identify factors that had an impact on their lives.	Identified nine thematic categories fell into three main categories: (1) the impact of the stroke event on caregivers; (2) the extrinsic factors that support the caring scenario; and (3) the natural factors that help caregivers to cope with the new role.
Green TL, King KM., 2009 [13]	To explore male patients with minor stroke and their wife-caregivers' perceptions of factors affecting the quality of life and caregiver strain.	Patients and caregivers identified two major themes that were 'being vulnerable' and 'realization.'
Pierce LL, et al. 2012 [14]	To examine the dimensions of the emotional strain of caring for stroke caregivers in a new family of stroke patients.	Caregivers worried about themselves and patients. The caregivers felt lost caregiving in their lives. Describing emotional strain when taking on new roles in caring for the person with stroke. Three themes: (1) being worried, (2) running on empty, and (3) losing self.
Tellier M, et al. 2011 [5]	To explore quality of life and the perception of spouses.	Six main themes: (1) Patients that made caregivers tired. (2) Daily living ADL, lack of time, and financial concerns. (3) Conjugal relationship on differing role, conflict, and positive aspects. (4) Relapse for plans, habits, and anxiety. (5) Need for services information and support. (6) health problems with sleep, emotions, tiredness, and physical symptoms.
White CL, et al. 2007 [15]	To explore the perceptions of caregivers regarding the barriers and facilitators to the role of caregiving.	Two themes of caregiving perceptions: (1) primary barriers on the role: lack of healthcare team collaboration and community support, caregiving role intensity, and the negative impact. (2) facilitative: coordination of care, the patient's progress to health, controlling the caregiving role, promoting a more social environment, and improving easy access to community resources.

Theme One: Level of the caregiver burden. The first theme found the level of the caregiver burden had five categories: (a) expressed as uneasiness; (b) expressed as nervousness; (c) expressed as aggressive behavior; (d) expressed as abandonment, and (e) expressed as sad emotion. Uneasiness was the first level that motivated caregivers to find some kind of help which would make it easier for them to cope. Caregivers may be concerned about their health and emotional feelings because they did not know how to solve their problems regarding these feelings.

Aggression took the form of certain behavior types, often described as anger, a loss of control, or sudden emotional outbursts. One of the studies reported male caregivers explaining that their outbursts took the form of a physical response to the difficulties they faced every day. Abandonment can be described as the actions which took place when caregivers became exhausted, were in denial, or became selfish. The studies reported that a number of caregivers either became more selfish or conversely ignored their own lives when caring for family members who had suffered stroke. In many cases, caring for the patient became their sole focus, leading the caregiver to devote their time and effort to the role while their own lives took on minimal importance. Sad emotions included bereavement, depression, guilt, sadness, isolation, and feelings of uselessness or stigmatization. Many families of stroke patients reported feeling guilty, while feelings of loneliness and a lack of happiness were also commonplace. Some had to do things alone as part of their care duties, which caused discomfort and feelings of unease. Previous studies of caregiving had also reported negative emotions and psychological distress which could be signs of reduced quality of life in terms of both health and social life. These categories could be difficult to measure or classify accurately, but had a broad adverse influence upon the health and well-being of caregivers.

Theme Two: Environmental factors of the burden. The second theme found the environmental factors of the burden. The caregivers in these studies stated that there were many factors in the environment which impacted their health and stimulated feelings which resulted in the burden. In one of the studies, it was explained that the main factors which increased the difficulty of the caregiver's role included the level of the patient's impairment, financial pressures, lack of support, the presence of other family members to share the burden, and the added burden of responsibility.

Caregivers also had problems when the other people around them failed to provide adequate support, or when they did not have access to the correct information about help which should be available to them through healthcare providers. Caregivers suggested that they became tired of working with healthcare providers as a result of their responsibilities, and that the stroke their family member suffered also had a negative impact upon their own lives. One caregiver reported that he was given minimal help by the healthcare providers as he was unable even to see the doctor responsible for the patient that he, the caregiver, was looking after.

Theme Three: Related illnesses from the burden. The last theme concerned the relevant illnesses from the burden and consisted of two categories: (a) pathological disease, and (b) physical illness that has its origins in the mind. Pathological diseases of caregivers were the structural and functional

changes in the bodies of the caregivers that were the physical symptoms of conditions such as fatigue, headache, pain, and weakness. The common physical symptoms included sleep problems, headaches, and a general lethargy and fatigue, although one caregiver was quoted observing that aches and pains was normal for older people. However, many of the caregivers in the studies reported fatigue as one of the causes of their inability to pay better attention to their own health.

Another category which was related to illness in caregivers of stroke patients was that of physical illness. The physical illnesses resulted from the mental state of emotional feelings of the caregivers. The symptoms expressed were similar to those of physical diseases, but they resulted from problems with mental health. These symptoms included drinking too much, fatigue, functional deficit, headaches, lack of energy, sleeping problems, and general weakness. A number of caregivers cited stress as the cause of their headaches, while others added that the physical aspects of their care duties were not as tiring or problematic as the mental or emotional aspects. Tiredness and a lack of opportunity to enjoy adequate sleep were common problems. Others explained that functional deficits and general weakness were outcomes which resulted from the stroke suffered by the family member. All of the themes are shown below in Table 3.

Table 3: Summary of themes, coding, and examples quotations from the data

Themes and subthemes	Coding	Example quotation
Theme one: Level of caregiver burden		
Expressed as uneasiness	emotional feeling, health concern, irritable, overwhelmed, tired, worn down, worn out	ID2: "The carers, particularly the older ones, were also concerned about their health." ID4: "They felt "exhausted," "overwhelmed," "irritable," "worn out," "worn down," and just plain "tired."""
Expressed as nervousness	annoyed, anxiety, distress, emotional strain, exhaustion, fear, frustrate, panic, stress, tension, worry	ID1: "they were more worried about the health." ID3: "when you do have a break most of the time, you are so worn out and exhausted." ID4: "participants reported emotional strain with day-to-day situations." ID6: "We did not get answers, which creates anxiety because we did not know how to plan." "There is so much worry; it is all unknown." ID7: "the wife-caregivers to alleviate the distress and anxiety engendered by the stroke event."
Expressed as aggressive behavior	Anger, emotional outbursts, lack of control	ID7: "It was the disability-associated experiences of the men, either physical or emotional, that elicited reactions of anger; Some men described their emotional outbursts as reactions to physical challenges being encountered in daily life; lack of control, feeling stigmatized, and being overwhelmed by the immediacy of the illness experience all led to a heightened sense of vulnerability for patients and their wife-caregivers."
Expressed as abandonment	burnt out, denial, Ignore yourself, selfish	ID2: "Towards an understanding of the lives of families affected by stroke feel selfish" ID5: "parent care became their first priority. They dedicated considerable time and the effort to the caregiving role and, as a result, their own lives and activities often became secondary"
Expressed as blue emotion	Depression, emotional lost, guilty, lack of enjoyment, loneliness, Separated from society, stigmatized, useless	ID2: "Towards an understanding of the lives of families affected by stroke feel guilty; you just feel that you are getting lost in there somewhere" ID3: "lack of enjoyment and loneliness; we used to go together, but I had to go alone, which wasn't too nice because I do not like to go out alone, but now I have to." ID7: "My emotional well-being has become significantly worse; The stroke has made me useless."
Theme two: Environmental factor of burden		
Autonomy, caring impact, consultation, family support, financial, Get pressure from others, gratitude, have a break, inadequate information, independence, knowledge, lack of information, lack of sexual performance, lack of support, life change, limit health professional support, losing self, lost work, over responsibility, personality change, received health services, relationship, shared of caring, social support, suffer from own disease, suffering stroke patients, supporting factor, uncertainty, well information		ID1: "With the stroke, my wife is unemployed, which has really reduced our income." ID2: "the impact of the stroke event on the carer; I never even saw the consultant he was under, never even saw a doctor." ID3: "Some common factors identified as making caregiving more difficult were increased responsibilities, degree of spouse's impairment level, additional caregiving roles for other family members, financial stress, and limited support." ID4: "discussing their feelings of fatigue with their healthcare providers." ID7: "Many wife-caregivers also experienced a loss of independence and autonomy, as they restructured their daily routines to accommodate the presence of the husband."
Theme Three: Related illnesses from the burden		
Pathological disease	Fatigue, headache, pain, weakness	ID1: "Physical symptoms such as headaches, difficulty in sleeping, and a lack of energy were reported by participants; At our age, it is normal to have pains" ID3: "Most of these participants cited fatigue and lack of time as reasons for neglecting their own health." ID7: "functional motor weakness accounted for some of this lack of independence.
Physical illness that results from the mind	drinking too much, fatigue, functional deficit, headaches, less energy, sleeping problems, weakness	ID1: "I have a lot more headaches because of the stress." ID4: "It was not always the physical work of caring that caused fatigue but it was also the emotional feelings that added to that tiredness; wanting to sleep late without the worry." ID6: "Fatigue was common in caregivers and the majority described times in their caregiving role when they felt completely overwhelmed." ID7: "physical loss, directly related to the functional deficits and weakness resulting from the stroke itself."

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Discussion

There were three themes of qualitative studies about the burden in stroke caregivers that emerged from seven related articles. The first theme mentioned the level of the caregiver burden in five parts, noting that the emotional burden can affect the health of the stroke caregivers. The first and second parts of this aspect were low level as mental discomfort or an emotional feeling, or perceiving events as irrelevant to their lives although it was possible to cope [10]. At the next level came more tension, but the stroke caregivers were still able to cope [4]. The feelings of annoyance, anxiety, distress, emotional strain, exhaustion, fear, frustration, panic, stress, tension, and worry were found. Many articles found that the caregivers needed to adapt in both physical and psychological terms [16-18]. Greater tension was expressed in aggressive behavior that may affect caregivers' health and result in illness, and this level can stimulate caregivers to display violent behaviors. The expression of abandonment and expression of sad emotions have a greater effect on caregivers' health. This knowledge reflected the fact that the stroke caregivers should understand and manage their feelings because these emotions not only impacted upon the health and illness of the caregivers but also impacted upon the stroke patients [3]. Stress theory of Selye (1956) reported that stress has three levels, the person who embraced the burden for a long time were susceptible to illnesses such as peptic ulcer and depression [16-20]. From the result, the first theme came from a variety of factors while environmental considerations were involved in the second theme. This theme affected their own health causing them to have health problems. Their symptoms came not only from the pathology of the diseases but many came from their inner feeling. From this knowledge it would be made easier for them to understand the environmental factors that affected their health. If the caregivers could manage the environmental factors influencing them, it might help them to manage their burden from caring for the stroke patients when they encountered barriers, and thus limited the impact of the burden. Managing these would help them to maintain good health and the potential to care for their loved one.

Conclusion

The integrative review of qualitative studies about the burden imposed upon stroke caregivers provided unique insights into the stroke caregivers' perceptions. The study proposed to explore and identify the burden in the caregivers who are caring for stroke patients in their homes, and is synthesized within themes. Three main issues emerged from the studies of the caregiver burden: (1) level of the caregiver burden; (2) environmental factors of the burden, and (3) related illnesses from the burden. This knowledge was up to date and extracted from the expression of behaviors responding to three themes which came from problematic factors. This allowed nurses or other healthcare providers to acquire a better understanding and could be used to create or design new ways to prevent the negative impact of the burden or managing the burden placed on the caregivers. The outcome of this would be that caregivers would be able to act with greater efficiency.

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