

## Conference Paper

# Family Experience as Caregivers in the Rehabilitation of Stroke Patients: A Literature Review

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**Abstract**

This study aims to summarize the research results on family experiences as caregivers in post-stroke patients' rehabilitation processes. The method of this study used a literature review. Google Scholar and PubMed were used to find Bahasa and English articles examining families as caregivers of stroke patients. These studies were assessed using the JBI critical appraisal tools for Qualitative Study with a total of 8 factors used to the quality of the selected articles. Nine articles were reviewed with JBI scores of about 90-100%. This study found 327 articles, and after quality assessment of these studies, nine articles came to review process. The review process generated six general aspects that have been summarized by researchers representing all emerging themes, namely physical, psychological, spiritual, economic, social, and family effort aspects. The results of this literature review hope can be a reference or provision related to families as caregivers.

**Keywords:** caregiver, family, experience, stroke

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## 1. Introduction

Stroke occurs due to blockage of blood vessels or rupture of blood vessels that carry blood and oxygen to the brain resulting in a lack of oxygen, causing the body's movement control function to malfunction [1]. Stroke is one of the diseases that burden the world due to the high death rate from stroke, which is the second-highest after heart failure. Also, stroke was reported to cause the world's highest dependence and disability level [2, 16], [18]. World Neurology reinforces that stroke is a burden because it requires high costs and prolonged treatment.

After having a stroke, a person will be more dependent on others in carrying out daily independent activities[3]. Efforts to restore the limbs are by doing rehabilitation.

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Rehabilitation also remedies functional disorders and helps alleviate those around post-stroke people and foster post-stroke people's enthusiasm[4]. Another study on family experience as a caregiver states that a family's presence in the rehabilitation process for post-stroke patients can improve the recovery process [5].

Families, as caregivers also experience serious physical and psychological problems [17]. The articles also mentioned that the psychological impacts family experienced were stress, anger, temperament, hopelessness, discomfort, boredom, and the physical effects experienced, namely fatigue, fatigue, dizziness, sleep problems, pain, and weakness [6]. The impact of the family response that appears can affect post-stroke patients' condition in the form of loss of enthusiasm for therapy and unwillingness to do ADL independently.

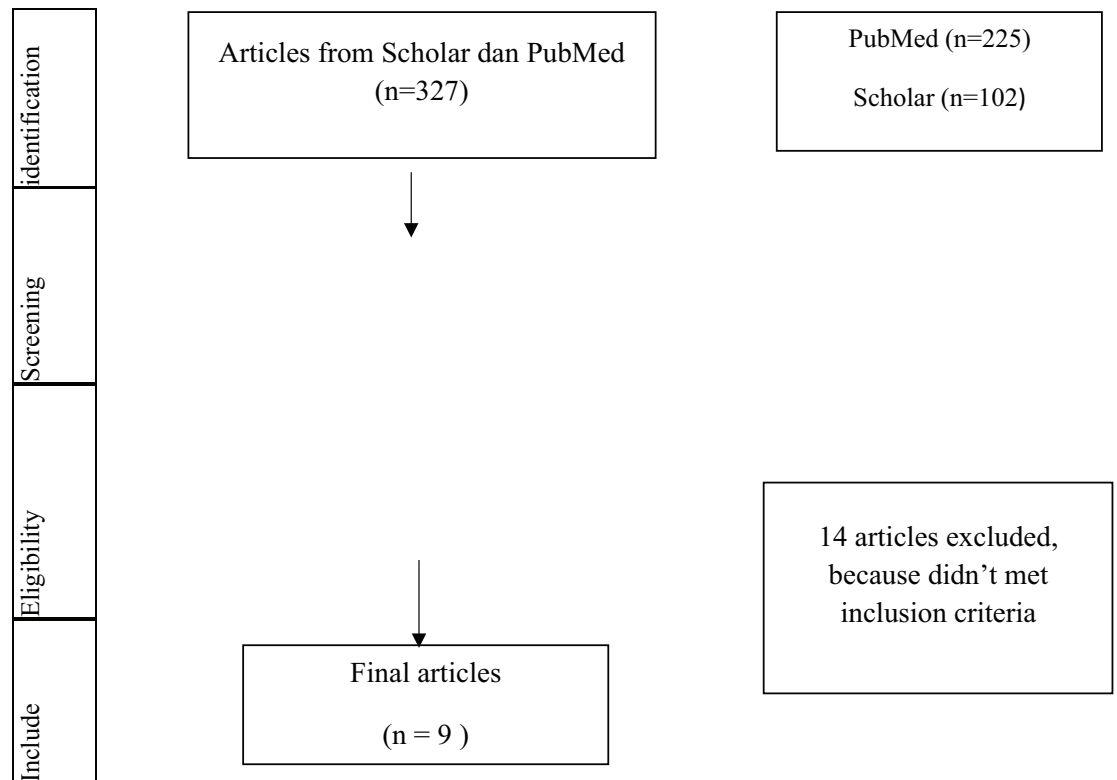
## 2. Method

This study method used a literature review. The keywords used in this study were *Stroke, Family, Caregiver, Qualitative*. Articles were searching using Google Scholar and PubMed with inclusion criteria of studies conducted on families as caregivers of stroke patients, delivered in Bahasa or English. The inclusion criteria for searching journals are studies conducted on families as caregivers for post-stroke patients, free full text, journals with Qualitative methods, delivered in Bahasa or English. The assessment of each article's quality was carried out using a standard format from The Joana Briggs Institute (JBI) Checklist for Qualitative Research Checklist, a total of ten items.

## 3. Results

After the reviewed process, nine articles met the inclusion criteria as final articles. A study conducted in Banjarmasin, Indonesia with a sample of 6 peoples, resulted in seven themes, namely changes in roles, economic impacts, changes in physical conditions, changes in psychological states, changes in social interaction activities, the timing of spiritual activities, and efforts done by the family [7]. Another phenomenological study in Indonesia

Family experiences involved six peoples as participants stated four themes: psychological adaptation, biological adaptation, social adaptation, and spiritual adaptation [8]. In Jambi, Indonesia, a phenomenological study with 9 participants resulted in four themes: dependence on daily activities, family efforts to fulfill self-care activities, constraints faced by caregivers, and family expectations [9].



**Figure 1:** Searching Summary

Similar research was conducted in several countries, such as in Taiwan, Srilanka, and the USA. A study in Taiwan was conducted with ten participants' grounded theory method resulting in four themes: chaos, high alertness, physical fatigue, and psychological and making a new life [10]. There are sub-themes on each theme, such as nervousness in the theme of chaos, high alertness as sub-theme of urgency, fear of health potential on the physical theme, and psychological anxiety, namely draining financial burdens, physical demands and takes time. The last theme is creating a new life for two sub-themes: learning to do and behavior adjustment.

Another qualitative study took family as a stroke caregiver was also conducted in the USA by two researchers. The study was conducted with eight participants who produced three themes: a collection of emotions, readjustment, and prevention [11]. There are eight sub-themes on the study: emotional problems, persistent worry, over-protection, multitasking, environmental support, taking action, restoring self-confidence, and making mistakes. Another study in the USA also produced three themes: difficulty managing uncertainty in the recovery process, difficulty managing emotional distress, sources of emotional distress[12].

A similar study conducted in Sri Lanka delivered one big theme, namely caring with love, which there are four sub-themes: life changes (increased workload, limitations in

social life, physical changes, and dependency), lack of resources (financial problems, deficiency of knowledge and lack of facilities at home), loving care (taking responsibility, dedicating full care), and coping strategies (self-strength, social support, and feeling valued) [13]. The study involved 26 participants generating one theme: *live on the edge* by bringing up four sub-themes: having total responsibility, being alone, being a prisoner in one's own life, and being uncertain about the future [14]. Qualitative research on family experiences has yielded unique and mixed results. Almost all research uses qualitative phenomenological methods, but some studies use Grounded theory and qualitative descriptive methods.

## 4. Discussion

All previous studies suggest that there are changes in various aspects of a family member who acts as a caregiver. Nine research articles state that six general aspects arise: physical aspects, psychological aspects, spiritual aspects, economic aspects, social aspects, and family efforts. The entire article generates themes related to physical aspects: physical fatigue, encouraging physical movement, nutritional considerations, facilitating movement or displacement, changing physical conditions, biological adaptation, dependence on daily activities, family efforts to fulfill self-care activities. The second aspect that emerged was the psychological aspect. Still, only eight articles presented the psychological aspect with the themes of high alertness, chaos, psychological restlessness, changing roles, changes in psychological conditions, psychological adaptation, difficulty managing emotional distress, difficulty managing uncertainty in the recovery process, sources of emotional distress, emotional accumulation, feelings of guilt, caring with love, living on the edge, and obstacles faced by caregivers.

The spiritual aspect is the third aspect that appears in 4 articles. They facilitate religious activities, the timing of spiritual activities, spiritual adaptation, and family expectations [5, 7–9]. The next aspect that emerges is the economic aspect explained by helping financial problems and economic changes [5, 7]. The last aspect is the aspect of family efforts in which there are several themes, such as creating a new life, filling free time, efforts made by the family, readjustment.

The physical aspects described in the studies are fatigue, dizziness, disturbed rest and sleep patterns, changes in blood pressure, difficulty moving, back pain. Besides that, the general aspects that are delivered are the psychological aspects: feelings of anger, disappointment, anxiety, feelings of guilt, sadness, and hopelessness. The social changes that occurred were the lack of interaction with others. The economic

TABLE 1: Family as Caregiver Studies

NO	PLACE		PARTICIPANTS	THEMES
	Ind	Other countries		
1[10]		<input type="checkbox"/>	Ten family member which involved in patients care for more than one month	Chaos Urgency feeling fear of potential harm Fatigue both physically and psychologically Creating a new atmosphere or a new pattern of life
2[5]		<input type="checkbox"/>	19 participants who involved in patients care	Help encourage physical movement Helping the dam provides facilities for personal hygiene Nutritional considerations for stroke patients Facilitating religious activities Fill in spare time Facilitating movement/displacement Assist in financial matters
3[7]	<input type="checkbox"/>		12 participants who involved in patients care	Role change There is an economic impact on the family The impact of changes in physical conditions during treatment There is a psychological impact Changes in interaction activities with residents Timing of spiritual activities experienced Family efforts to providing care for stroke's patients
4[8]	<input type="checkbox"/>		The family member who lives in the same house with a patient	Psychological adaptation Biological adaptation Social adaptation Spiritual adaptations
5[12]		<input type="checkbox"/>	the family member involved in patients care	Difficulty managing uncertainty in the recovery process Difficulty managing emotional distress Emotional distress source
6[11]		<input type="checkbox"/>	Eight family the member involved in patients care	Finding the meaning in life and readjustment during recovery.
7[13]		<input type="checkbox"/>	the family member involved in patients care	Increase in workload Limited social life Physical problems Knowledge deficits Financial problems Inner strength and Social support can help
8[14]		<input type="checkbox"/>	Twenty-six participants involved in stroke patients care	Exciting life changes Creating unstable situations Can reduce their well-being Make his own decisions
9[9]	<input type="checkbox"/>		Nine family member which involved in patients care for more than one month	Patient dependence on family Family efforts to fulfill self-care activities Constraints faced during treatment Family expectations of stroke sufferers

changes are described as an economic decline due to stroke conditions. The average family gets economic assistance from retirement money or managing assets abandoned like gardens and farms [5]. Other studies stated economic changes happened from

spending a large amount of money. They must pay for treatment either at the hospital and home, resulting in families having to sell their assets, spend all their savings, and give up their daily needs cost [7, 9]. Social and spiritual changes or adaptations are described as a lack of interaction. The family often cannot attend important family events such as weddings and gatherings [7–9].

The themes emerged from the nine selected articles, and the different themes emerged from each article. One study explains that besides the physical and psychological impacts, there are other themes: *high alertness* and *creating a new life* [10]. The high alertness described in this article is vigilance for stroke sufferers because of disturbances in defecation and bowel movements so that families overcome problems of elimination and pay attention to feelings, health, and hygiene of stroke sufferers. Another theme mentioned is creating a new life interpreted by two sub-themes: *learning by doing* and attitude adjustment. Another study has several different themes: *total responsibility*, *feel alone*, *feel uncertain about the future*, and *become prisoners in their own lives* to the conclusion that exciting life changes and creating An unstable situation can reduce their well-being [14]. The number of sources that create emotional distress also comes as a different theme in this study [12].

All articles provide themes that describe the existence of adaptations or changes in the family. A common theme also appears in all articles related to family efforts on stroke patient's care. The family's efforts are given to meet basic needs, such as eating, activities, elimination, personal hygiene. Besides, the efforts gave are also in the form of medication, training in mobilization, and spiritual fulfillment [15]. The efforts provided by the family are to help stroke survivors recover, but that does not mean that the family does not experience obstacles in providing care. There are themes regarding obstacles that families must face. These obstacles are conflicting desires related to caring, being busy with work, lack of family assistance or support, lacking care's knowledge and skill, difficulties in meeting basic needs for stroke sufferers, social activities changes, and lack of economy [9, 11].

The family as a caregiver must have positive coping through think positively, in the form of strengthening determination to focus on patient health, self-strengthening, self-empowerment, get closer to God, doing hobbies, or exercising [12, 13]. The caregiver experiences manifested during the stroke patient's caring period. The family experiences this manifestation, but the patient will feel the impact of the caregiver changes. While family or caregiver helps in a state of fatigue, emotion and is less gentle, the patient will show an uncomfortable attitude and tend to be silent or even don't want to be helped [10]. The physical changes felt by the caregiver will have an impact on

the caring family process. The families help patients to the bathroom clean themselves, such as bathing, defecating, and urinating, by hugging and carrying the patient to the bathroom. But while the family feels Very tired and unable to do that, the patient must feel it [7]. Stroke patients will have better improvement in the right family support setting. It will make post-stroke patients more enthusiastic about the rehabilitation process and faster recovery rates than post-stroke patients who lack family support.

The whole article has various themes, some are the same, and some are different. At the end of the article, it describes the theme of family expectations as caregivers: *the family hopes*. The family hoped that the patient's condition could recover soon to carry out activities as usual. The family was also expecting assistance from the health team to provide knowledge or training on treatments that must be given to stroke survivors.

## 5. Conclusion

Based on the literature review results carried out on nine articles, several conclusions can be drawn. The themes raised vary depending on family coping, the patient's condition, and the severity of the disease. There are general aspects raised by each article's themes, namely physical aspects, psychological aspects, spiritual aspects, social aspects, economic aspects, and aspects of family efforts.

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