

Challenges in home care for stroke patients: how caregiver resilience relates to patient disability levels

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Research Article

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Abstract

Aim

This study aimed to evaluate the relationship between family caregiver strength and the disability level of stroke patients receiving home care in Hamadan city.

Methods

A descriptive-analytical study involved 180 stroke patients and their family caregivers, selected through convenience sampling in Hamadan, Iran. Participants completed a 4-part questionnaire (demographic data of patients and caregivers, Sixby resilience, and the Barthel Index) during a 25-minute clinic visit. SPSS 26 software was used for data analysis.

Results

Caregiver resilience scores showed that 5% were Low, 37/8% were Medium, 45% were Much, and 12/2% were Very much, with a mean score of $173/56 \pm 6/62$. According to the Barthel scale, 14/5% were completely dependent, 63/3% Relative dependent, and 22/2% were independent, resulting in a mean score of $87/22 \pm 4/78$. A significant relationship was found between Barthel scale scores and resilience ($R = 0/72$).

Conclusion

The study indicated an inverse relationship between caregiver resilience and patient disability levels. Despite high caregiver resilience, there was no statistically significant correlation between resilience and caregiver demographics or between patient demographics and their Barthel Index scores. These findings highlight the necessity for improved support for stroke survivors' caregivers through targeted interventions.

Introduction

Are the challenges of stroke too overwhelming to bear? Stroke is the most significant chronic neurological disease in adults and the third leading cause of death globally [1]. It is also the most typical reason for prolonged adult impairment. It results from acute brain dysfunction, leading to difficulties in performing daily activities and becoming partially or fully dependent on others [2]. More than 30% of stroke survivors report complete or partial dependence in daily activities [3]. The inability of patients to care for themselves creates confusion for family caregivers, complicating their ability to meet basic needs [4]. Common complications, such as impaired walking, muscle weakness, sensory deficits, cognitive decline, and reduced mobility, further stress caregivers [5]. Family caregivers score higher on

caregiver burden inventories than other caregivers because they bear the primary responsibility for daily care [6]. Many caregivers feel unprepared for their new responsibilities and face significant challenges in rehabilitation, resulting in higher stress levels compared to caregivers of other chronic neurological patients [7]. Understanding the needs of stroke caregivers in home care visits can alleviate challenges [8]. Caregivers often face challenges such as changing family roles, reduced income, sleep deprivation, limited leisure time, and work-related stress [9]. Conversely, a lack of home care services and clinical guidelines increases readmission rates due to complications [10]. The caregiving burden on family members significantly impacts their physical, mental, emotional, economic, and social health, leading to confusion [11]. Mental health, a crucial aspect, can deteriorate under psychological stress from caring for terminally ill patients [12]. Resilience can mitigate the adverse effects of caregiving stress. It involves positive adaptation and skill development to counteract the negative impacts of illness [13]. Strong communication, minimal family conflict, and mutual support are common in families with good interpersonal relationships and are defined as resilience [14]. Family resilience specifically refers to a family's capacity to adapt and regain balance in crises, influencing mental health, quality of life, and hope [15].

Family caregivers face significant stress as they balance caring for a disabled stroke survivor with necessary lifestyle changes [16]. The varied needs of stroke survivors include physical (mobility and transport), communication (interactions with family and friends), nursing (hygiene and medication administration), emotional and psychological (social withdrawal and fatigue-related libido decline), and financial (income and treatment costs) aspects [17]. Many family members experience high levels of stress while caring for these individuals, which not only diminishes their quality of life but also negatively impacts the patient's emotional well-being, hindering their rehabilitation and potentially exacerbating depression [18]. However, research on family resilience, particularly in acute stroke patients, is limited, focusing more on individual coping strategies. This study aims to explore the correlation between family caregivers' resilience and the disability level of stroke patients in home care in Hamedan.

Method

This study is descriptive-analytic and correlational, focusing on stroke patients and their primary caregivers receiving home care in Hamadan, Iran. The study population included stroke patients (ischemic and hemorrhagic) and their family caregivers who met specific inclusion criteria. A sample size of 180 was determined based on a 95% confidence level, 80% test power, and a 0.5 effect size using G*Power 2.1.9.2 software. Convenience sampling was employed at the neurology department of Besat Hospital, Hamadan. Inclusion criteria for family caregivers included: at least elementary education, over 18 years of age, a familial relationship with the patient, serving as the primary caregiver for at least 2 days a week for at least 2 months, and no history of specific psychological illness as self-reported. For patients, the inclusion criteria specified: experiencing a first-time stroke, being discharged to home care for at least two months, and reporting no specific psychological illness. Exclusion criteria included unwillingness to participate and incomplete questionnaire submissions. Data collection tools involved: 1. Patient demographics (age, sex, economic status, marital status, stroke type, and disability). 2.

Caregiver demographics (age, sex, patient relationship, degree, family income, care frequency per week). 3. Family resilience assessment, using a modified 66-item scale developed by Sixby (2005), reduced to three subscales: communication/problem solving, religious/social resources, and problem acceptance [19]. The four-point Likert scale scores ranged from 66 to 264, with higher scores indicating greater resilience. In this study, 25 caregivers completed the resilience questionnaire, showing a reliability of 0.85 [1]. 4. Barthel index checklist, comprising ten daily activities evaluated through caregiver interviews, categorizing patients into complete dependence (score 0–40), limited dependence (41–99), or independent (100) [7, 20]. The researcher conducted the study with permission from Hamadan University of Medical Sciences and approval from the center officials. Informed consent to participate was obtained from all of the participants. After completing a written informed consent form, patients were assured that their information would be kept confidential and anonymous. The data collection targeted stroke patients receiving home care who had sought further treatment at a specialized stroke clinic, evaluated against entry criteria. The researcher was present at the clinic in a quiet environment to explain the research objectives and the questionnaire completion process. Patients and their primary caregivers received the personal information questionnaire in sealed envelopes, with a completion time of about 25 minutes. Some questionnaires were filled out at home, while others were completed in the clinic. The confidentiality of information and anonymity of participants were upheld at all stages of the research, conducted following the ethical principles of the Declaration of Helsinki. Data analysis used SPSS 26 with statistical tests at $p < 0.05$. Descriptive statistics included percentages, frequencies, means, and standard deviations; hypothesis testing involved correlation, ANOVA, and multiple regression.

Result

The study examined 180 patients and their family caregivers, with a mean patient age of $58/62 \pm 4/38$ years and a mean caregiver age of $33/78 \pm 5/62$ years. Additional demographic characteristics are detailed in Table 1. Based on the resilience scale, scores showed that 5% were Low, 37/8% were Medium, 45% were Much, and 12/2% were Very much, with a mean score of $173/56 \pm 6/62$. According to the Barthel scale, 14/5% were completely dependent, 63/3% Relative dependent, and 22/2% were independent, resulting in a mean score of $87/22 \pm 4/78$. (Table. 2) The relationship between the total score of the Barthel scale and resilience was examined through the Pearson correlation coefficient, and the results showed that these two scales have an inverse and significant relationship ($P\text{-value} < 0.05$) (Fig. 1). The Pearson correlation coefficient was used to examine the relationship between the total Barthel score and resilience. The results showed that there was a strong and significant direct relationship between patient disability and caregiver resilience ($r = -0.72$, 95% CI: -0.92 to -0.82 , $p = 0.008$) (Table 3).

Table 1. Demographic characteristics of stroke patients and their family caregivers

Variables	N (%)	P-Value
Patients		
Sex		0.361
Male	(57/2) 103	
Female	(42/8) 77	
Marital Status		0.281
Married	(68/9) 124	
Single	(31/1) 56	
Income		0.149
Low <200\$	(47/2) 85	
Medium 200-500 \$	(32/8) 59	
Much >500 \$	(20) 36	
Stroke Type		0.562
Ischemic	(71/7) 129	
Hemorrhagic	(28/3) 51	
Disabilities		0.412
Right hemiplegia	(13/3) 24	
Left hemiplegia	(18/9) 34	
Visual disorder	(12/2) 22	
Mobility disorder	(22/8) 41	
Urinary disorder	(10/5) 19	
Multiple disorder	(22/2) 40	
Family Caregivers •		
Sex		0.288
Male	(27/2) 49	
Female	(72/8) 131	
Family relationship		0.365
Spouse	(25/5) 46	

Brother	(10/5) 19
Sister	(10) 18
Parents	(7/7) 14
Children	(46/3) 83
Degree	0.456
High school	(32/8) 59
Diploma	(25/5) 46
Master's & bachelor's	(41/7) 75
Income	0.378
Low <200\$	(43/3) 78
Medium 200-500 \$	(36/1) 65
Much >500 \$	(20/6) 37
Care days	0.741
< 2 days a week	(32/2) 58
2-5 days a week	(50) 90
>5 days a week	(17/8) 32

Table 2
Patient and caregiver positions based on disability and resilience

Variables	Category	N (%)	P-Value
Resilience	Low	9 (5)	
	Medium	68 (37/8)	
	Much	81 (45)	
	Very Much	22 (12/2)	
Disability	Complete Dependent	26 (14/5)	
	Relative Dependent	114 (63/3)	
	Independent	40 (22/2)	
Significant: P < 0/05			

Table 3
Correlation coefficient between the resilience scale and Barthel

Variables	Mean $\pm$ SD	R (Pearson)	P-Value
Resilience	173/56 $\pm$ 6/62	0.72	0 < 0/001
Disability	87/22 $\pm$ 4/78		

Discussion

The current study explores the relationship between family caregivers' resilience and the disability level of stroke patients. The findings reveal a significant inverse correlation (P-value < 0.05) between resilience and disability, with a correlation coefficient of 0.72 indicating that greater disability is associated with higher resilience in caregivers. This relationship reveals the challenges stemming from the disease, including financial, physical, psychological, emotional, and social issues. The problems faced by family caregivers and their consequences often overshadow the matter of care. Supporting this, Fang et al. (2022) found that family caregivers of stroke patients face substantial mental health burdens, particularly spouses and parents. The caregivers' capacity to care is linked to their circumstances—such as education, income, employment, relationship with the patient, daily caregiving time, and cohabitation—which correlate with depressive symptoms. Caregiving burden correlates positively with psychological symptoms, but resilience mitigates these effects, enhancing caregivers' ability to endure challenging situations [21]. Family resilience emerges as a response to stress, allowing families to adapt to challenges, including chronic illness, and is crucial for member health. Handayani et al. (2024) demonstrated resilience's mediating role in improving caregivers' quality of life. Interventions fostering resilience in palliative care can notably enhance caregiver well-being [23]. Nooreddini et al (2024) showed that dealing with stress, a healthy lifestyle, and coping with the patient's problems were extracted from resilience in the perception of family caregivers of stroke patients. Family caregivers of these patients gradually develop resilience due to the patients' incapacity, the demanding nature of care, ongoing health issues, and numerous challenges, making them more adaptable to significant care concerns. They demonstrate thorough and patient care, enabling patients to complete their rehabilitation programs [3]. Zhou et al. (2024) identified that caregiving burden is influenced by stroke survivors' dependency, caregiver education, health, and daily care time, with family resilience mediating the burden and capacity relationship. Enhancing family resilience can effectively reduce caregiving burdens, prompting healthcare staff to assess resilience in stroke patients' families and implement supportive interventions [24]. Han et al. (2024) pointed out that family functioning remains a pivotal factor in resilience despite caregiving challenges. Qualitative analysis revealed four themes in family adjustment: loss of independence, facing challenges, leveraging family resources, and adopting coping strategies. This adaptation process helps caregivers accept their circumstances and plan accordingly, ultimately promoting family well-being and reducing caregiving burdens [25].

Karmpourian et al. (2024) highlighted a significant inverse relationship between caregiving burden and client resilience [13]. Similarly, Keniş et al. (2020) found that the caregiving burden and resilience of parents with children suffering from neurological conditions are negatively related. This may indicate that caregivers with lower resilience tend to respond poorly to life's challenges. In contrast, informal caregivers, particularly in home care, with higher resilience experience lower caregiving burdens, even when facing high patient demands. Resilient caregivers employ active coping strategies, enhancing their caregiving abilities, which in turn may reduce the caregiving burden [26]. Although this study indicated a high resilience level among family caregivers, regression analysis revealed no significant relationship between resilience and demographic factors. This finding aligns with Feng et al. (2022), who found no significant association between family adjustment and demographics [21]. Furthermore, a regression analysis examining the relationship between patient disability levels, based on the Barthel Index, and demographic information yielded non-significant results. Nooredini et al.'s study showed that full-time caregiving, coupled with personal challenges and psychological issues such as anxiety and depression, heavily impacts caregivers. Concerns about patient loneliness and mobility often disrupt family life, creating stress for spouses of chronic patients. Families with long-term sick members typically experience a diminished quality of life, regardless of demographic differences [7].

These findings were consistent with those of Masoudian et al., showing no statistically significant relationships between age, economic status, education, and patient disability levels [22]. In this study, most stroke patients exhibited moderate disabilities, resulting in moderate to high caregiver dependence. Economic resources, financial status, and social support are known to influence resilience. A significant portion of participants had financial independence with moderate to low incomes, potentially contributing to their low resilience. This contrasts with Feng et al. (2022), where the average caregiving burden score for stroke caregivers was reported at 43.89, indicating a high burden according to the Zarit Caregiving Burden Questionnaire. Both studies utilized the Barthel tool to assess stroke patients' disability severity, revealing that many patients had moderate to severe disabilities [21]. Finally, Israfil et al showed practical and important results in their study. They noted that stroke is a chronic disease that profoundly affects all aspects of a person's life, increasing the dependency on family caregivers and presenting significant challenges for them. Caregivers face various difficulties, from emotional stress during the diagnosis to physical and social challenges in home care, which worsen with complications like swallowing disorders, severe disabilities, or psychological issues such as depression and anxiety. Factors such as the caregiver's employment status, education level, kinship ties, social support, understanding of stroke rehabilitation, transition from hospital to home, and access to healthcare and social activities all contribute to these challenges. Education, psychosocial support, and improved access to health and rehabilitation services can help alleviate the caregiving burden [27]. Generally, higher patient disability correlates with greater caregiver dependency and increased caregiving burden. Severe strokes often lead to uncertainty about prognosis, hindering caregivers' ability and lowering their quality of life, which can negatively impact caregiver resilience over time. Effective management of caregiving challenges can enhance the adaptation of stroke patients and support family caregivers in the management process (Fig. 2).

Implication

This study demonstrated a close relationship between resilience and disability, highlighting that psychological, physical, social, financial, and emotional factors are crucial for care planning and understanding the needs of family caregivers of stroke and other chronic patients.

Limitations

Study limitations included fatigue and burnout from caregiving responsibilities, along with incomplete cooperation from participants in questionnaire completion. However, a key strength of this study was that participants were included at least two months post-hospital discharge, as caregivers were not primarily responsible for care during hospitalization. This timing helps ensure that findings reflect true caregiving burdens. Additionally, initial screening based on stroke severity aids in refining the specificity and homogeneity of the study population.

Conclusion

As shown in the present study, there was an inverse correlation between the resilience index of family caregivers and patients' disability. Also, despite the high level of resilience in caregivers, there was no statistically significant relationship between resilience and demographic information. There was also no statistically significant relationship between patients' demographic information and their level of disability based on the Barthel index. Considering the results of this study and previous research, it seems necessary to pay closer attention to the resilience category among caregivers of stroke survivors to further strengthen this potential resource through appropriate measures. Based on the findings obtained, one of the relevant factors in caring for disabled and dependent stroke patients is resilience, and it is recommended that health policymakers and those responsible for developing education and health, especially home care, strengthen the resilience of families and primary caregivers of clients to strengthen all aspects of health, including physical, mental, spiritual, economic, cultural, and social. Fatigue and exhaustion resulting from accepting responsibility for the patient's care, the patient's inability to care for himself, and the transfer of responsibility to the family were the most important limitations of the study. Lack of cooperation or incomplete cooperation in completing the questionnaires was another limitation of the present study. The fact that at least 2 months had passed since the patients were discharged from the hospital for their entry into the study was one of the strengths of the present study, because at the beginning of this disease and during their hospitalization in the hospital, their caregivers were not in the position of caregivers. Most of the care was the responsibility of nurses. In such circumstances, the burden of care for their caregivers does not make much sense. Also, initial screening of patients based on the severity of disability due to stroke helps to make the study results more specific and homogenize the studied population.

Abbreviations

ANOVA
Analysis of Variance
SPSS
Statistical Package for the Social Sciences

Declarations

Ethics approval and consent to participate

The content of this article was conducted in accordance with the ethics code IR.UMSHA.REC.1399.570as determined by the Research and Ethics Committee of Hamadan University Medical Sciences. Patients completed informed consent. The confidentiality of information and anonymity of participants were upheld at all stages of the research, conducted following the ethical principles of the Declaration of Helsinki.

Consent for publication

Not Applicable

Competing Interests

The authors declare no conflicts of interest.

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Author Contribution

Conception and design, Drafting the article, revising the article: Ahmad Nooreddini.

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Data Availability

Due to the sensitive nature of the questions asked in this study, survey respondents were assured that raw data would remain confidential and would not be shared. Data are not available, and the data that have been used are confidential.

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Figures

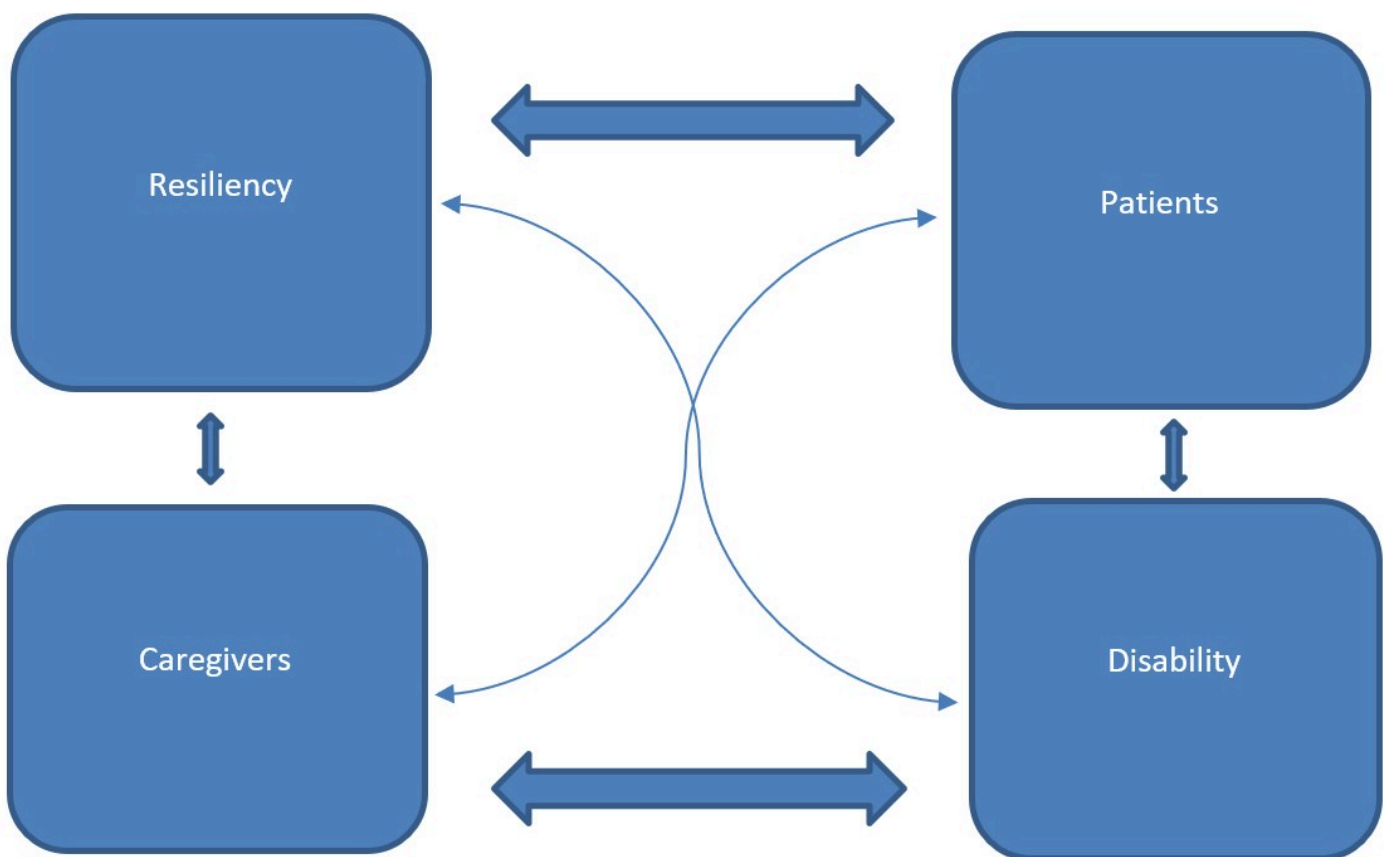


Figure 1

Patient Disability and Caregiver Resiliency

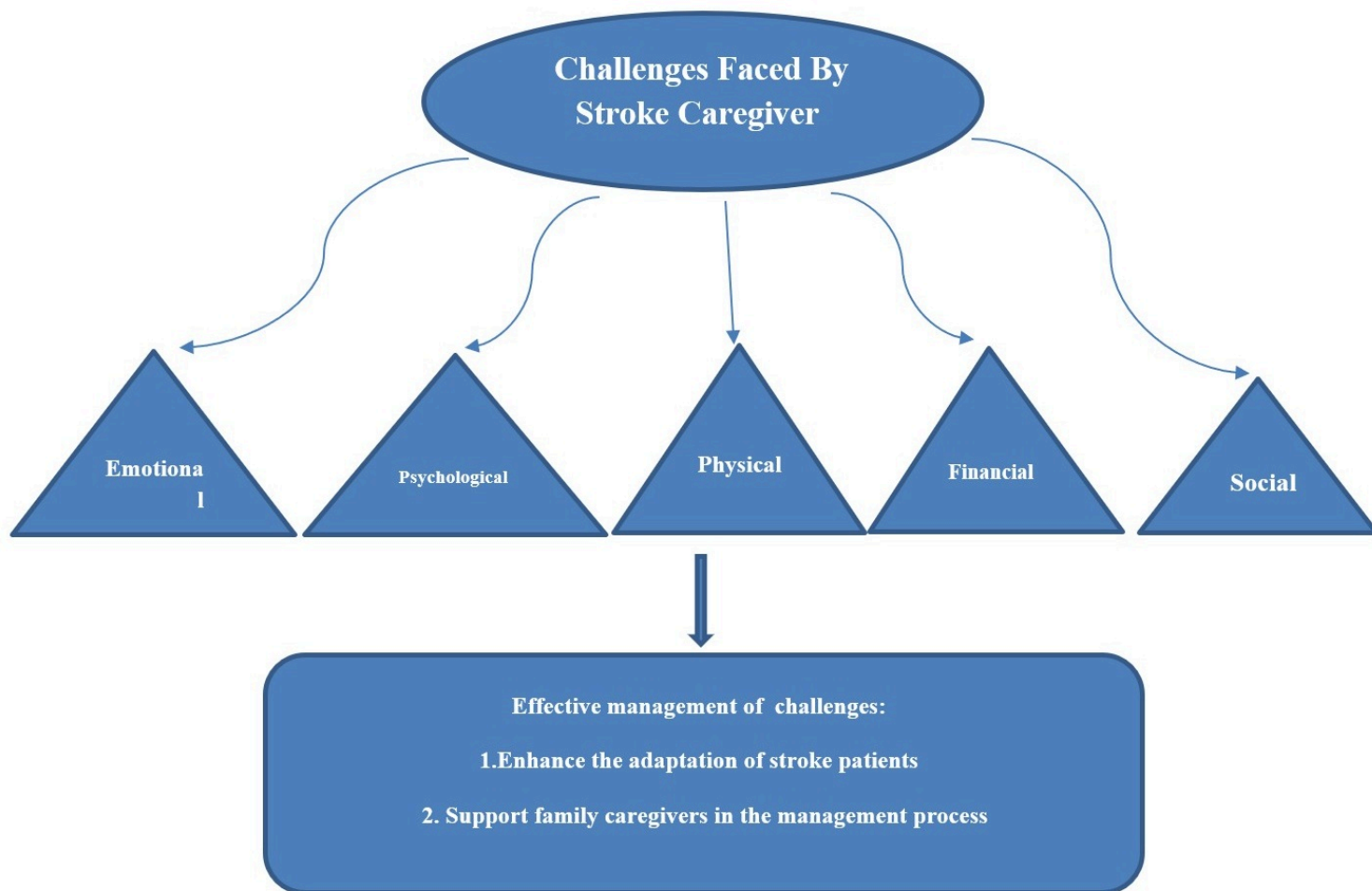


Figure 2

CVA Caregivers Challenges