

Family caregiver's burden of patients with stroke and its predictive factors

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Abstract

Background: Two third of patients with stroke, in the first episode of stroke would be survived and need care and rehabilitation. This situation influences the patients' survivals and the routine life of family caregivers. This study aimed at investigating the care burden of family caregivers who provided care for patients with stroke at home.

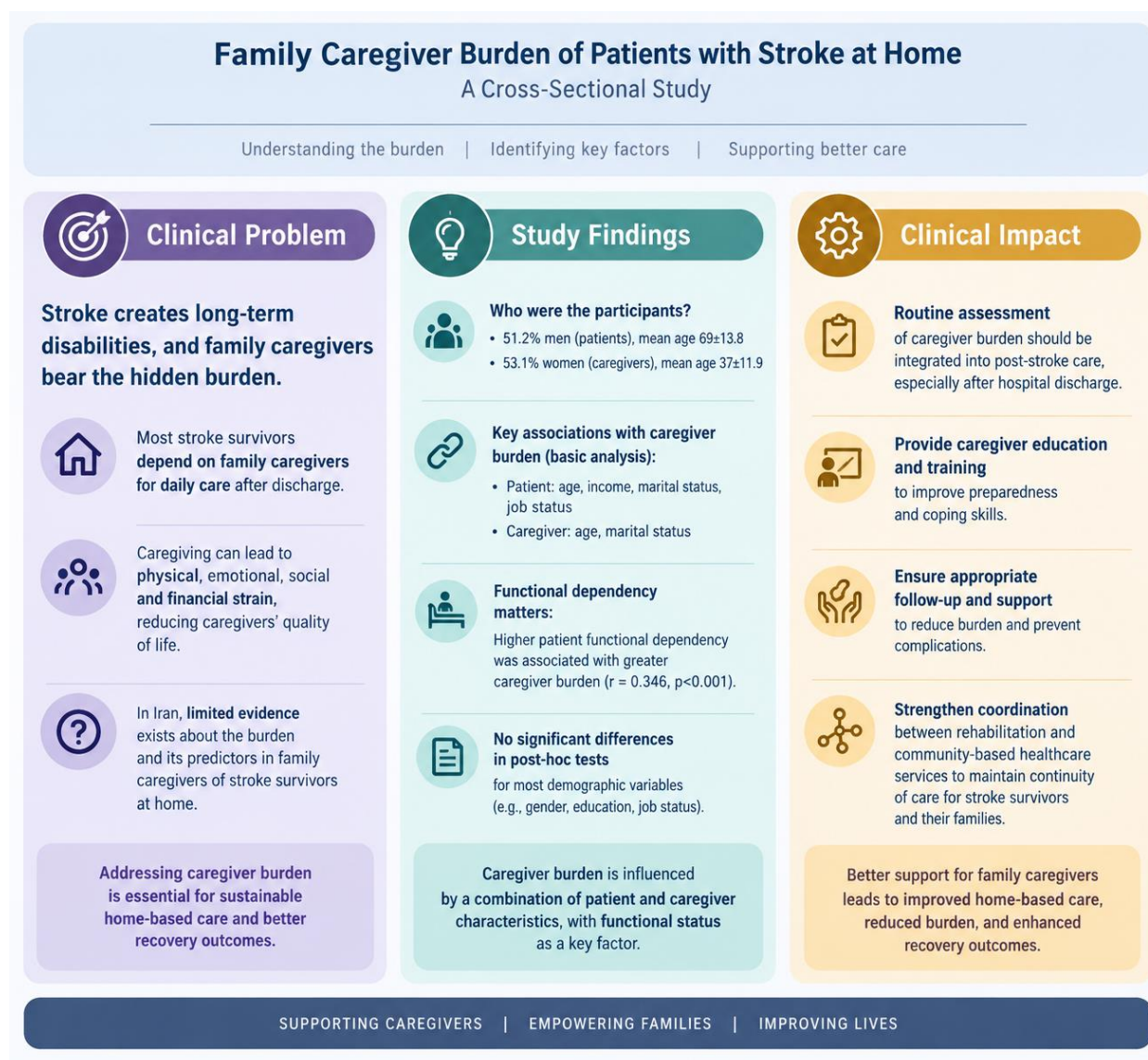
Methods: This cross-sectional study included 254 patient-caregiver pairs recruited by convenience sampling in 2019–2020. Participants were stroke patients receiving home care for at least one month and their family caregivers. Data were collected using a demographic questionnaire, the Bakas Caregiving Outcomes Scale, and the 10-Item Modified Barthel Index. Data were analyzed using SPSS 17. One-way ANOVA with Tukey's post-hoc test assessed differences in caregiver burden, and Pearson's correlation assessed the relationship between patient functional dependency and caregiver burden.

Results: Most patients were men (51.2%), with a mean age of 69.13 ± 11.87 years and stroke duration of 25.14 ± 14.02 months. Most caregivers were women (53.1%), with a mean age of 37.94 ± 11.30 years and a caregiving duration of 25.90 ± 13.30 months. Caregiver burden was weakly associated with patients' age ($p=0.043$), income ($p=0.011$), marital status ($p<0.001$), and occupation ($p=0.025$), as well as caregivers' age ($p=0.002$) and marital status.

Conclusion: The patients and the family caregivers' characteristics were not strong predictors of caregiver's burden in our research. The reasons might be that the physical, cognitive and health status of the stroke survivors were not very severe. Establishing home care services, long-term care institute, empowering family caregivers by training and supporting them are essential approaches to prevent and reduce the care burden.

Implications for Patient Care: Routine assessment of caregiver burden, caregiver education, and appropriate post-discharge support may facilitate home-based care and improve continuity of care for stroke survivors and their families.

Keywords: Burden, Family caregiver, Informal caregiver, Primary caregiver, Stroke.



Graphical Abstract. Family Caregiver Burden in Patients with Stroke Receiving Home Care: A Cross-Sectional Study. Family caregivers of stroke survivors may experience substantial caregiving burden after discharge to home. In this study, caregiver burden was associated with several patient and caregiver characteristics, while greater patient functional independence was associated with more positive caregiver outcomes ($r=0.346$, $p<0.001$). These findings highlight the importance of routinely assessing caregiver needs, providing individualized education and training, and ensuring appropriate post-discharge follow-up. Strengthening coordination between rehabilitation and community-based healthcare services may support caregivers and promote more sustainable home-based care.

Introduction

Stroke causes severe and chronic disabilities and it is the third factor of mortality in the world (1). Two third of patients with stroke, in the first episode of stroke would be survived and need to rehabilitation (2, 3). This situation is not predictable for the survivals and family

caregivers (FCs) and influences their routine life (4). Indeed, stroke as a life-threatening event develops physical and psychological disabilities which would place them in various risks such as respiratory aspiration, lack of integrity of skin, hypothermia, joint contracture, mal-nutrition, verbal communication deficit, decreased sensory

perceptions and disrupted thinking processes. Thus, the patients based on the disabilities and self-care deficits require different care needs (5). Since, many cares for the patients should be provided by professionals, conducting them by family caregivers might be problematic for the patients and family caregivers.

Providing care to patients by family members has a vast impact on daily life of them (1). So family caregivers are the second victim of the chronic diseases such as stroke (6). If family caregivers are not prepared and do not have enough readiness to accept care responsibility, they might be at risk of care burden (7). Negative effects of the care burden in various dimensions including physical, psychological, social, emotional and economical aspects, reduce the quality of life (QOL) in family caregivers (8, 9). Care burden threatens all family members but it is more much common in member who are main and primary caregiver at home (10). In study by Kavi et al., anxiety, exhaustion, decrease of family interactions and ignorance of psychological and educational needs emerged as main categories in caring patients (1). Rawat et al. revealed that most of informal caregivers had severe level of care burden which influenced their emotional health and interactions (8). In study by Kaur et al., 73.5% family caregivers of patients with stroke experienced high level of strain (3). Different factors related to patients or family caregivers might influence the burden perceived by family caregivers. Preparedness of family caregivers is an influential factor, so that Ain et al., found family caregivers who had stress due to lack of training experienced high level of stress, sleep disorders and difficulty in the management of family life (6). The functional level of patients is a determinative factor for burden level, so that in study by Celi and Karu, caregivers of patients with less functional abilities had higher level of burden and lower QOL (2, 3).

Although care burden is significant, caring at home is essential and indispensable part of health system throughout the world. On the other hand, chronic diseases like stroke are not predictable in terms of longevity and time of healing (11). Lack of following the stroke patients and their families by the health system results in they would be unknown. While, following them by the health system is critical to meet their needs. Determining care burden perceived by family caregivers and implementing care at home by professionals is influential to prevent care burden and its complications for families and family caregivers. Nevertheless, we found limited published studies associated to care burden in family caregivers of patients with stroke in Iran which their sample size was low (12, 13). Therefore, this study was conducted to investigate the care burden of family caregivers who care patients with stroke at home.

Materials and Methods

Study Design and Setting

This cross-sectional study was conducted between November 2019 and June 2020. Patients with stroke were recruited from the lists of neurology units of educational hospitals affiliated with Lorestan University of Medical Sciences (LUMS) and rehabilitation centers in Khorramabad city.

Participants and Eligibility Criteria

Detailed information about the patients was obtained from the available lists. Family caregivers were then screened by telephone according to the inclusion criteria. The inclusion criteria for family caregivers were being a correspondent caregiver providing care for patients who had been discharged for at least one month, providing care without payment, and having no previous experience of caring for patients with chronic diseases. Family caregivers

with previous experience of caring for patients with chronic diseases were excluded. There were no excluded cases. The inclusion criteria for patients were being male or female and having experienced stroke and being cared for at home by family caregivers for at least one month.

Sample Size and Sampling

The primary sample size was calculated based on similar studies, considering $r = 0.23$, $\alpha = 0.05$, and $\beta = 0.10$, resulting in a sample size of 195. Due to the possibility of refusal by caregiver-patient couples to participate in the study, the final sample size was determined as 254 participants, including a 30% design effect. Sampling was performed using a convenience sampling method.

Ethical Considerations and Data Collection

After obtaining approval from the Research Ethics Committee of LUMS (IR.LUMS.REC.1395.167), screening of potentially eligible caregivers was initiated. To obtain informed consent, participants were provided with explanations regarding the study purposes, confidentiality and anonymity of the data, and their right to refuse participation. Written informed consent was obtained at the time of data collection.

Participants completed the questionnaires through face-to-face interviews either during home visits or when they attended rehabilitation centers for physiotherapy. No participants refused to participate, and 254 questionnaires were completed.

Study Variables and Demographic Characteristics

Patients' characteristics, including age, gender, marital status, educational status, job status, amount of income, duration of disease, and the presence of other diseases, were considered as independent variables. Caregivers' characteristics

included age, gender, marital status, educational status, job status, duration of providing care, and amount of income. Patient functional independency was also considered as an independent variable. A questionnaire was used to collect demographic data from the family caregivers and patients.

Family Caregiver Burden

The dependent variable was the mean score of family caregiver burden, which was measured using the Bakas Caregiving Outcomes Scale (BCOS). This scale was developed by Bakas. It consists of 15 items based on a 7-point Likert scale, ranging from significant negative change (−3) to significant positive change (+3). The average score for each item is calculated separately, as well as for the entire scale. Higher scores indicate more positive outcomes of care.

The scale was translated into Persian, and its psychometric characteristics were assessed. First, during the forward translation step, the original version was translated from English into Persian by two bilingual experts. During the backward translation phase, it was translated back into English. The approved Persian version was then assessed in terms of validity and reliability. The I-CVI for the scale ranged from 0.80 to 1, and the S-CVI was 0.96. The K* score for all items was higher than 0.79, representing an excellent level of content validity.

Construct validity was assessed using confirmatory factor analysis. The fit indices were CFI = 0.989, GFI = 0.962, IFI = 0.989, TLI = 0.975, RMSEA = 0.059, $\chi^2 = 80.991$, $df = 47$, and $p < 0.001$. Standardized factor loadings for all items were significant and ranged from 0.51 to 0.88 ($p < 0.001$). Item 13, "my relationship with patient with stroke," was the only item with a value below 0.40 and was subsequently deleted. Internal consistency was assessed using Cronbach's alpha coefficient, which was 0.94.

Patient Functional Independency

The other independent variable was the mean score of functional independencies, which was measured using the Barthel Index (BI). This index is the most common scale used to assess functional independency in patients with stroke. The 10-item version developed in 1981 as the Collin version was applied. The index was translated into Persian, and its psychometric characteristics were assessed. First, during the forward translation step, the original version was translated from English into Persian by two bilingual experts. During the backward translation phase, it was translated back into English. The approved Persian version was then assessed in terms of validity and reliability. The I-CVI ranged from 0.80 to 1, and the S-CVI was 0.99. The K* score for all items was higher than 0.79, representing an excellent level of content validity.

Construct validity was assessed using confirmatory factor analysis. The fit indices were CFI = 0.998, GFI = 0.981, IFI = 0.998, TLI = 0.996, RMSEA = 0.035, $\chi^2 = 24.800$, $df = 19$, and $p < 0.167$. Internal consistency was assessed using Cronbach's alpha coefficient, which was 0.96. The mean range of scores for each item was between 0 and 6, and the total mean score of the scale ranged from 0 to 84. Higher mean scores indicated lower care burden among family caregivers.

Statistical Analysis

SPSS software version 17 was used for data management. The Kolmogorov–Smirnov test showed that the variables had a normal distribution ($p > 0.05$). ANOVA and Pearson's correlation, were conducted to identify predictors of family caregiver burden. The total score of the scale ranged from 10 to 33, with higher scores indicating higher independency of patients.

Results

Results showed the majority of family caregivers were older than 38 years (34.6%), women (53.1%), married (64.2%), with educational level of diploma (37%), unemployed or housekeeper (41.7%), with moderate income (45.7%) and care duration of 2 months (58.7). Moreover, the majority of the patients were at age range of 65-77 years (34.3%), men (51.2%), married (86.6%), illiterate (64.2%), unemployed or housekeeper (56.7%), with moderate income (47.6%), 2 months of affected by stroke (54.7%) and with other diseases (83.9%).

Relationship between demographic characteristics of the patients and care burden in their family caregivers

In this study, based on One-way-ANOVA test, there were significant statistical relationship between care burden in family caregivers and some demographic characteristics of the patients consist of age ($p=0.043$), amount of income ($p=0.011$), marital status ($p=0.00$) and job status ($p=0.025$). In Post-Hoc analysis by Tukey's Test, there were not significant differences between various level of ages, two genders, three groups of marital status, four types of jobs of the patients in terms of care burden of their family caregivers. The relationship between demographic characteristics of the patients and their caregivers' burden are presented in table 1.

Relationship between demographic characteristics and care burden in family caregivers

In this study, based on One-way-ANOVA test, there were significant statistical relationship between care burden in family caregivers with some demographic characteristics of them consist of age ($p=0.002$) and marital status ($p=0.000$). In Post-Hoc analysis by Tukey's Test, there were not significant differences between various level of

ages and three groups of marital status in terms of care burden of the family caregivers. The relationship between demographic characteristics

and care burden in the family caregivers are presented in table 2.

Variable		Care burden	
		M±SD	p-value
Age, years	No (Percent)		0.043
< 65	82 (32.28%)	56.24±14.64	
65-77	87 (34.25%)	51.10±13.98	
> 77	85 (33.46%)	56.38±18.00	
Amount of income, Toman			0.011
<500.000	80 (31.5%)	50.52±16.04	
500.000- 1.000.000	121 (47.6%)	55.45±15.33	
>1.000.000	53 (20.9%)	58.47±15.31	
Duration of affected by disease, month			0.909
< 2	139 (54.7%)	54.28±17.26	
2-8	30 (11.8%)	54.00±13.10	
> 8	85 (33.5%)	55.12±14.15	
Gender			0.054
Female	124 (48.8%)	56.48±16.60	
Male	130 (51.2%)	52.66±14.76	
Marital status			0.00
Single	13 (5.1%)	47.84±13.33	
Married	220 (86.6%)	53.73±14.82	
Widow	21 (8.3%)	67.04±20.81	
Educational status			0.229
Illiterate	163 (64.2%)	53.27±15.98	
Under diploma	65 (25.6%)	55.52±17.14	
Diploma	14 (5.5%)	59.92±8.13	
Academic education	12 (4.7%)	59.91±8.76	
Job status			0.025
Employed	19 (7.5%)	50.63±12.77	
Retired	31 (12.2%)	62.22±20.25	
Self-employed	60 (23.6%)	54.43±13.01	
Jobless	144 (56.7%)	53.43±15.73	
To be affected by other diseases			0.562
Yes	213 (83.9%)	54.78±16.62	
No	41 (16.1%)	53.21±10.38	

Table 1. Relationship between demographic characteristics of the patients with care burden in their family caregivers (N=254)

Variable	Care burden		
		M±SD	p-value
Age, years	No (Percent)		0.002
< 30	85 (33.5%)	50.74±15.60	
30-38	81 (31.9%)	59.34±16.38	
> 38	88 (34.6%)	53.76±14.33	
Amount of income, Toman			0.064
<650.000	93 (36.6%)	51.52±15.83	
650.000-1.000.000	116 (45.7%)	56.57±16.56	
>1.000.000	45 (17.7%)	55.46±12.57	
Duration of providing care, month			0.325
<2	149 (58.66%)	54.31±17.25	
2-5	19 (7.48%)	59.68±11.72	
>5	86 (33.86%)	53.76±13.66	
Gender			0.675
Female	135 (53.1%)	54.14±16.38	
Male	119 (46.9%)	54.97±15.10	
Marital status			0.00
Single	75 (29.5%)	48.14±11.30	
Married	163 (64.2%%)	57.15±17.03	
Widow	16 (6.3%)	57.68±11.98	
Educational status			0.266
Illiterate	39 (15.4%)	56.74±15.67	
Under diploma	75 (29.5%)	54.29±14.70	
Diploma	94 (37%)	52.41±17.83	
Academic education	46 (18.1%)	57.36±12.54	
Job status			0.778
Employed	32 (12.6%)	55.00±11.25	
Retired	17 (6.7%)	54.94±16.98	
Self-employed	99 (39%)	54.59±16.16	
Jobless	106 (41.7%)	53.33±16.48	

Table 2. Relationship between demographic characteristics and care burden in family caregivers (N=254)

According to the Pearson correlation coefficient, there was a direct significant correlation between functional dependency in patients and care burden of the family caregivers ($r=0.346$, $p<0.001$). In other words, with the increase of Bartel's scores of functional independence, the

scores of Bakas care burden also increase and vice versa.

Discussion

Stroke survivors live with varied degrees of disabilities and care is provided for them largely by family caregivers (4). Providing care to

patients with stroke is a dilemmatic phenomenon in terms of physical and emotional dimensions for caregivers. Burden is common negative outcome in caring these patients for caregivers (4). In a cross-sectional study done in Kenya, the level of informal caregiver burden was found to be moderate in 58.6% of the caregivers while 40% had mild or no burden (14). In study by Gbiri et al., in South Africa, most of participants (60.8%) reported moderate objective burdens while 79.2% had mild subjective burdens (4). Indeed, high percentage of family caregivers experience moderate to severe depression. Also, the major factors that contributes to burden is financial, social and psychological problems which they are faced during the care process (14). The amount of burden and its predictors are different because communities' contexts are different. In Iran where these patients should be provided care by family caregivers at home after discharge, the predictors might be different. Therefore, this study was done to identifying burden predictors in Lorestan province where have variant context from capital and other cities in Iran.

One part of the findings, was related to characteristics of patients with stroke and their family caregivers. It was revealed the most patients with stroke were men, married, housekeeper or unemployed, with no education, with moderate income and had co-morbidities. Furthermore, the most family caregivers were women, married, housekeeper or unemployed, with education of diploma and with moderate income. The most patients were men but the most caregivers were women who were usually the wife of the patients. Moreover, the patients and their caregivers were often married. In contrast our study, in a study in south Africa, involved 157 informal caregivers, the majority of them were

men (81 males and 76 females) (4). But in consistent with this study, based on the review by Xiong et al. (2020), 66.8% caregivers in different studies were women (15). In study by Nishio et al., 75% percent of the patients were male, although 90% of caregivers were female (16). This fact accepted that in different cultures, caring is duty of women and because of that family caregivers often are female.

In this study the mean ages of the patients and the family caregivers were 69 ± 13.78 and 37 ± 11.94 years, respectively. Indeed, caregivers were younger than the patients and they are expected because the caregivers had spousal or offspring relationship with the patients. In a study in Kenya, the caregivers constituted of adult offspring at 50.7%, spouses at 24.1% and siblings at 13.8%. Also, many studies have shown caregivers usually had spousal relationship with patients (15). Their mean age was 36.2 years and 54.5% were females. (14). In consistent with our study, in study by Gbiri et al., the patients' mean age was 59.6 ± 14.6 years and the informal caregivers' mean age was 39.2 ± 12.8 years (4). In study by Hekmatpour et al., the mean age of caregivers was 48.52 years (17). In the study by Watanabe et al., patients and their caregivers were spouses and had nearly the same ages (18). Based on study review by Camak, many stroke survivors were in their sixth decade of life or older, with caregivers approximately the same age (19).

In this study, most of the patients and their caregivers were unemployed with moderate income. It is fully expected because in the one hand, the most caregivers were patients' wife who are usually housekeeper. On the other hand, patients and their caregivers would miss their job and it is why to decline the family income.

In other part of our results, in assessing the relation of the patients' characteristics with the family caregivers' burden, the findings revealed association between age, marital status, job situation and income with family caregivers' burden. Moreover, in assessing the relation of the family caregivers' characteristics with burden in them, the results revealed association between age, and marital status with family caregivers' burden. It is worth to note, although we found relationship between mentioned items with family caregivers' burden in basic test, we didn't find differences between various levels of the mentioned items in post-hoc test. Therefore, the findings are interpreting cautiously.

According to our finding, ages of the patients and the caregivers might be related to family caregivers' burden, so that who were older experienced higher burden. This kind of talk cautiously is because basic test showed significant differences between 3 ages levels but in post-hoc test there was not any differences. In truth, there are studies with various findings in regard with this issue.

The result showed there was no significant relationship between gender of the patients and the caregivers and the perceived burden of caregiving which shows that the perceived burden of caregiving is independent of the gender. Study by Xiong et al., suggested the presence of gender differences in caregiving burden, so that female caregivers experienced greater burden compared to their male counterparts. It worth noting, they claimed while most of the included studies on caregiving burden demonstrated a higher level of burden among female family caregivers, but it can be associated with gender-based analyses in this area without considering other factors such as age, and time spent on caregiving and disease severity (15). In

the study by Kumar et al., higher level of burden could be partially explained by caregivers' characteristics in term of female gender, and private employment (9). While in study by Nishio et al., male patients experienced more burden (16).

In this study, despite there was relation between marital status with the perceived burden by caregivers in basic test (higher burden in caregivers who were married and provided care for married patients), we didn't find differences between three kinds of marital status in post-hoc test, so the findings are interpreting cautiously. In truth, there are studies with various findings in regard to this issue. In a study, to be alone in terms of marital status was significantly associated with the moderate burden of the caregivers (17). It might be due to limited the number of caregivers as well as the emotional connection between patients and their caregivers.

Despite there was relation between amount of income with perceived burden by caregivers in basic test (higher burden in caregivers who had higher income), we didn't find differences between three levels in post-hoc test, so the findings would be interpreted cautiously. In truth, there are studies with various findings in regard to this issue. Providing informal care for stroke survivors for a very long period of time may lead to the loss of the caregivers' job and a reduction in their earning that it would place them in lower income situation (20). Despite to this study, in a study by Hekmatpou et al., the burden caregivers was significantly associated with lower economic status (17).

Despite there was relation between job status with perceived burden by caregivers in basic test (higher burden in retired caregivers who provided care for retired patients), we didn't find differences between three types of job in post-hoc

test, so the findings would be interpreted cautiously. In truth, there are studies with various findings in regard with this issue. In the study by Kumar et al., higher level of burden partially explained by caregivers' characteristics such as private employment (9). In study by Mahinda, caregivers who were employed had significantly more burden (14). These differences might be because the retired caregivers had more free time to care. While in mentioned study caregivers should handle their works with caring concurrently and due to exhaustion, they felt more burden.

The results revealed there was no significant relation between educational status of the patients and the caregivers and the perceived burden of caregiving. In study by Hekmatpou et al., higher educational level of caregivers was associated with lower caregiving burden (17). Educated caregivers may have a more realistic understanding of a patient's condition and clinical changes and its implication on their prognosis than those with low educational attainment. This could influence their ability to adequately cope with the stress of caregiving (20).

The result indicated there was no significant relation between duration of affected by stroke in the patients and caring duration by caregivers with caregiving burden in family caregivers. In contrast, in study by Gbiri et al., in South Africa, longer duration since the onset of stroke and more hours of caregiving per day were factors which caused more level of burden and strains in informal caregivers (4).

In this study, functional independency of patients with stroke was another factor which was correlated with family caregivers' burden. In consistent with this study, study by Çelik1, and Kara showed relationship between the stroke

survivors' functional status and their caregivers' burden and quality of life. The caregivers' quality of life decreased and their care burden increased as the functional status of the patients deteriorated (2). Moreover, Watanabe et al. in a survey during 1999 to 2010 in Japan studied family caregivers of patients with CVA and found they perceived caregiving as burden but did not indicate deterioration in the family relationship. In another word, regardless of degree of independence of patients, caregiver burden was severe (18).

Conclusion

To sum up, these patients and the family caregivers' characteristics were not strong predictors of caregiver's burden in our research. The reasons might be that the physical, cognitive and health status of the stroke survivors were not very severe, or compared to the caregivers' characteristics and family resources factors, the patients' characteristics might not be the most important factor among the stroke survivors. Regardless of dependency degree of the patients to conduct ADLs, caregivers' burden is not indispensable. Therefore, supporting families with patients affected by stroke should be planned in the health system. Establishing a home care plan which support the families in various dimensions such as providing needed professional care, financial and social support is critical as well. These plans will reduce and prevent care burden in family caregivers by presenting care services, reduce care time, and allow them more free time (18). These patients can have acceptable progression in recovery process if their family caregivers would be empowered in providing care. Therefore, health practitioners have to make them ready to handling this situation at home by applying of

training and well-designed discharge plan. Considering long-term institute for care patients or preparation and support of family caregivers are essential as well. The most likely limitation in this study might be recall bias because the tools used to gather data were questionnaires. Moreover, the caregivers might not fulfill the questionnaires precisely due to frustration and fatigue.

Implications for Patient Care

Family caregiver burden should be considered as part of post-stroke care, particularly after discharge to home. Routine assessment of caregiver needs, functional dependency of stroke survivors, and relevant social and economic factors may help healthcare professionals identify families requiring additional support. Individualized discharge education, caregiver training, and appropriate follow-up after discharge may facilitate home-based care and help caregivers manage their responsibilities. Coordination between rehabilitation services, healthcare professionals, and community-based support services may also improve continuity of care for stroke survivors and their families.

Author Contributions

All authors contributed to the conception and design of the study, literature search, data interpretation, drafting of the manuscript, and critical revision of the article. All authors approved the final version of the manuscript and agree to be accountable for all aspects of the work.

Conflict of Interest

The authors declared no conflicts of interests.

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Ethics Statement

The authors confirm that all ethical principles of research and scientific publication, including plagiarism prevention, data integrity, and avoidance of duplicate publication, were fully observed.

Data Availability Statement

The datasets generated and/or analyzed during the current study are available from the corresponding author upon reasonable request.

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Author Contributions

All authors contributed to the conception and design of the study, literature search, data interpretation, drafting of the manuscript, and critical revision of the article. All authors approved the final version of the manuscript and agree to be accountable for all aspects of the work.

Publisher's Note

The graphical abstract was prepared by the journal's editorial team using artificial intelligence-assisted design tools and was reviewed and approved by the authors prior to publication.

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