

Research article

The relationship between the stroke survivors' functional status and their informal caregivers' burden and quality of life

Aysegül Çelik^{1,*} and Belgüzar Kara²

¹ Department of Pediatrics, Dr. Behçet Uz Child Disease and Pediatric Surgery Training and Research Hospital, Izmir, Turkey

² Department of Internal Medicine Nursing, Yüksek İhtisas University Faculty of Health Sciences, Ankara, Turkey

* Correspondence: Email: aysegul.g.celik@gmail.com; Tel: +05419237739.

Abstract: *Background and purpose:* Stroke is a major cause of disability and affects the lives of both the patients and their caregivers. The purpose of the study was to determine the relationship between the functional status of stroke survivors and the care burden and quality of life of their informal caregivers. The relationship between selected socio-demographic variables and the caregivers' caregiving experiences, quality of life, and care burden also was investigated. *Methods:* This cross-sectional study consisted of 100 patients and informal caregivers dyads. The Patient and Caregiver Information Form was used to collect demographic data; the Functional Independence Measure (FIM) and Barthel Index (BI) were used to assess functional status; the Caregiver Burden Scale (CBS) and 36-Item Short-Form Health Survey Quality of Life Scale (SF36-QLS) were used to assess the caregivers' burden and quality of life. Data were evaluated using descriptive statistics, Kolmogorov-Smirnov test, and parametric and non-parametric tests. *Results:* The mean FIM and BI scores of the patients were 61.0 ± 30.0 and 42.6 ± 28.3 , respectively. The caregivers' average score in the SF36-QLS subscale of general health perception was 51.7 ± 22.7 ; their average CBS score was 39.2 ± 13.8 . The caregivers' quality of life was found to be moderate to high in the domains of physical function, social function, mental health, bodily pain, and general health, but low in the domains of physical role function, emotional role function, and vitality. There was a negative correlation between the average FIM and BI scores of stroke survivors and their caregivers' CBS scores or scores on the SF36-QLS subscale of general health perception. *Conclusion:* There is a 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.

Keywords: caregiver; stroke; functional status; care burden; quality of life

Abbreviations: FIM: Functional Independence Measure; BI: Barthel Index; CBS: Caregiver Burden Scale; SF36-QLS: 36-Item Short-Form Health Survey Quality of Life Scale; CVDs: Cerebrovascular diseases

1. Introduction

Cerebrovascular diseases (CVDs) are the diseases that manifest with the blockage or bleeding of the vessels feeding the brain. CVDs are the second most common cause of death and the leading debilitating disease in developed societies [1,2]. Two-thirds of patients survive the first stroke episode, and the survivors need rehabilitation to gain speech, walking, writing, or other basic skills [1,3].

The functional status of stroke survivors is affected depending on the size of the neurological deficit after the stroke and about half of the survivors suffer chronic disability and become dependent for their daily life activities [4]. The upper extremity use and functional walking are often adversely affected in these patients; multidimensional limitations arise in functional areas such as sensory, speech, swallowing, perception, etc. These patients who become dependent in various levels need the support of caregivers starting with the acute phase of the disease and throughout the home care process. Thus, the quality of life of stroke survivors is adversely affected, and family members who take responsibility for the care of the patient experience physical, psychosocial, and economic problems and bear a burden related to caregiving [4–6].

The caregiver burden is a multidimensional concept including the physical and psychosocial aspects of individuals and requires keeping the balance between variables such as appropriate time; economic resource; psychological, physical and social status; role change; and identification of new roles for care [7]. Several factors were suggested that influence the caregiver burden, including the socio-demographic characteristics of the caregiver, the degree of the relationship to the patient, the duration of caregiving, co-residency with the patient, responsibilities outside of the caregiver role, disruption of social activities and family routines, disengagement from professional life, and the financial consequences of the disease [8,9]. These factors and long-term caregiving to stroke survivors have adverse effects on caregiver burden and quality of life of the caregivers [10–12]. McCullagh et al. [10] demonstrated that the caregivers' quality of life was associated with factors such as older age, increased functional dependence, and deteriorated emotional status of the patients and with the factors such as the age, gender, emotional status, education level, and perceived social support level of the caregivers. Similarly, White et al. [11] have shown that the behavioral changes in stroke survivors negatively impact caregivers' quality of life. It was reported that caregivers for stroke survivors also bear a caregiving burden and this burden significantly reduces their quality of life [12].

However, the studies evaluating the overall effect of functional status in stroke survivors on caregiver burden and quality of life are limited. To the authors' knowledge, there are no studies on this subject in the field of nursing in Turkey. In stroke and other chronic health problems with increased need for care, it is important for nurses to consider the patient and the caregiver together, to evaluate the factors affecting the caregivers' burden and quality of life, and to intervene accordingly in order to maintain the wellbeing of patients and caregivers. Understanding the relationship between the functional status in stroke survivors and the caregiver's burden and the quality of life is prerequisite for introducing caregiving practices tailored for stroke survivors, for the arrangements to improve caregiver's quality of life, and for maintaining a quality patient-care process. Thus, the aim of this study was to determine the relationship between the functional status in stroke survivors and the informal caregivers' care burden and quality of life. The study also explored the relationships of selected socio-demographic variables and caregiving experiences of informal caregivers to their quality of life and care burden.

2. Materials and methods

This was a cross-sectional study; the study population consisting of 140 stroke survivors who met the selection criteria and have stayed in the neurological rehabilitation units of a Training and Research Hospital's Department of Neurology and of a Rehabilitation and Care Center between October 2013 and February 2014, and their informal caregivers. The sample of the study consisted of 100 stroke survivors and 100 caregivers who stayed in the units during the study period and met the criteria for inclusion in the study. The inclusion criteria were as follows: The caregiver is responsible for the care of the patient for at least 1 month, the caregiver's physical and cognitive health condition is suitable for participation, the stroke survivor and caregiver volunteer to participate in the research, and the caregiver understands and speaks Turkish. Caregivers who did not meet the specified inclusion criteria were excluded from the study.

2.1. Data collection tools

2.1.1. Introductory information form for stroke survivors and caregivers

This form, which consisted of two sections and was created by the authors based on literature review, recorded the socio-demographic and medical data of the stroke survivors and the socio-demographic data and care-giving experiences of the caregivers. The first section consists of 14 questions to characterize the stroke survivor in terms of age, gender, marital status, educational status, occupation, income level, health insurance, place of residence, duration of illness, type of stroke, area of brain lesion, lesion size, presence of other diseases with stroke. The second section includes 16 questions evaluating the data related to the caregiver such as age, gender, marital status, education, number of children, occupation, income, place of residence, health insurance, relationship to the patient, co-residence with the patient, duration of caregiving, previous experiences, and caregiving-related training experiences.

2.1.2. Functional Independence Measure (FIM)

The FIM was used to evaluate the functional status of the stroke survivors. The validity and reliability study for FIM in Turkey was carried out by Küçükdeveci et al.; the correlation coefficient was found 0.90 [13]. This measure consists of two sections: motor skills (13 items) and cognitive skills (5 items). Two sections contain 18 items collected in 6 main domains (self-care, sphincter control, mobility and transfer, locomotion and walking, communication and social cognition). Each item is graded 1–7, evaluating the patient's dependence/independence status in activities involving these items; 1–2 points mean dependence, 3–5 points partial-dependence, and 6–7 points independence. The scale score ranges from 18 (complete dependence/total assistance) to 126 (total independence) [13].

2.1.3. Barthel Index (BI)

This index, developed by Barthel and Mahoney and adapted to Turkish by Küçükdeveci, was used to determine the patients' level of independence in their activities. The internal consistency coefficient was found 0.93 in the validity and reliability study of the Turkish version. It is used as a global assessment tool for all patients with sensory and motor deficits. This index evaluates the physical disability in daily life activities such as eating, bathing, grooming, dressing, bowel control, bladder control, toilet use, transfer to/from bed, mobility, and stair climbing in 10 items. The rating ranges from 0 (full dependence) to 100 (independence). The scores above 60 in this index are interpreted as the ability to function independently. A score between 0 and 20 is interpreted as full dependence, 21–61 as high degree of dependence, 62–90 as moderate dependence, 91–99 as minor dependence, and 100 as complete independence [14].

Two different assessment instruments, FIM and BI, were used together since a comprehensive and sensitive disability evaluation of the functional status of the stroke survivors was intended.

2.1.4. Caregiver Burden Scale (CBS)

The CBS was used to assess the difficulty in providing care for a stroke survivor who is in need of care as perceived by the caregiving individual. This scale was adapted to Turkish by İnci and Erdem. The scale uses Likert-type evaluation and consists of 22 expressions that define the effect of caregiving on the life of the caregiver. Possible scores in this scale range from 0 to 88 points. The items in the scale are focused on the social and emotional aspects, and a high scale score indicate a higher degree of difficulty experienced. The internal consistency of the scale was found 0.91, test-retest reliability was 0.86, and inter-observer consistency was 0.63. The internal consistency coefficient of the Turkish form was reported as 0.95 and the test-retest consistency coefficient was 0.90 [15].

2.1.5. Short-Form Health Survey Quality Of Life Scale (SF36-QLS)

The SF36-QLS was used to determine the quality of life of individuals who provide care for stroke survivors. This scale was developed by Ware and was designed to evaluate the physical and mental health [16]. The validity and reliability study of the Turkish version was done by Pınar [17];

the Cronbach Alpha internal consistency coefficient of the scale was found 0.92 and the test-retest reliability coefficients varied between 0.73 and 0.90. The scale evaluates the health-related quality of life and consists of 36 items in 8 subscales: Physical functioning (10 items), social role functioning (2 items), physical role functioning (4 items), emotional role functioning (3 items), mental health (5 items), vitality (4 items), bodily pain (2 items), and general health perceptions (5 items). Evaluation is done with Likert-type scale except for some of the items and is based on the last 4 weeks. The subscales assess the health between 0–100 as poor health (0) and good health (100) status.

The analyses of the domains of SF36 were explained in 8 subscales. The SF-36 questionnaire was used as a tool to holistically assess health-related quality of life. In congruence with the World Health Organization's definition of health, health-related quality of life refers to the overall conditions of the quality of life of ill or healthy individuals in accordance with the following eight domains: (a) limitations in physical activities because of health problems, (b) limitations in social activities because of physical or emotional problems, (c) limitations in role activities because of physical health problems, (d) bodily pain, (e) general mental health, (f) limitations in role activities because of emotional problems, (g) vitality, and (h) general health perceptions of an individual or a group measured in terms of feelings of satisfaction or dissatisfaction.

2.2. Ethical aspects of the study and steps followed

The data were collected following the approval of the ethics committee of the hospital dated 5 August 2013 and numbered 1491-1751-13/1648.4-1912. The stroke survivors and their caregivers were informed and their consents were obtained; then the Data Collection Forms were applied. The data were collected in face-to-face interviews with the patients and caregivers and from patient records. Each interview lasted about 15–20 minutes.

2.3. Evaluation of data

SPSS 15.0 package program was used in the evaluation and statistical analysis of the data. The descriptive statistics were given as counts and percentage for counted variables, and as mean, standard deviation, median, and minimum-maximum for the measured variables. The Kolmogorov-Smirnov test was used to examine whether the data had normal distribution or not. Student's t test, Mann-Whitney U test, one-way analysis of variance (ANOVA), and Kruskal-Wallis test were used in the comparative analyses. Pearson and Spearman correlation coefficients were used for the evaluation of the relationship between the two variables.

3. Results

The mean age of the stroke survivors was 65.2 ± 15.2 years; the majority were 55 and over (77.0%), male (58.0%), married (81.0%), had an education level of elementary school or lower (63.0%), and were not employed (81.0%). The majority of the survivors had incomes more than or equal to their expenses (78.0%), lived in the cities (61.0%), and had social security coverage (94.0%). The mean duration of illness was found 17.6 ± 23.8 months; 81.0% were diagnosed with ischemic stroke; and 71% had another comorbid disease.

The patients' functional status, as indicated by BI and scores in various sub-dimensions of FIM, is summarized in Table 1. The caregivers' socio-demographic characteristics are given in Table 2. The caregivers' mean SF36-QLS and CBS scores were given in Table 3.

Table 1. Mean scores the stroke survivors on Functional Independence Measure and Barthel Index (N = 100).

Measures	Sub-dimensions	Mean \pm SD	Median	Min–Max
Functional Independence Measure	Self-care	19.9 \pm 9.8	19.5	6.0–42.0
	Eating	4.5 \pm 1.9	5	1.0–7.0
	Grooming	3.5 \pm 1.8	3	1.0–7.0
	Bathing	2.9 \pm 1.6	3	1.0–7.0
	Dressing—upper body	3.0 \pm 1.7	3	1.0–7.0
	Dressing—lower body	2.9 \pm 1.6	3	1.0–7.0
	Toileting	2.8 \pm 1.7	2	1.0–7.0
	Sphincter control	7.4 \pm 4.2	8	2.0–14.0
	Bladder management	3.6 \pm 2.1	4	1.0–7.0
	Bowel management	3.7 \pm 2.1	4	1.0–7.0
	Mobility	9.2 \pm 5.3	9	3.0–21.0
	Bed, chair, wheelchair	3.1 \pm 1.7	3	1.0–7.0
	Toilet	3.0 \pm 1.7	3	1.0–7.0
	Tub, shower	3.0 \pm 1.7	3	1.0–7.0
	Locomotion	6.0 \pm 3.5	5.5	2.0–14.0
	Walk or wheelchair	3.1 \pm 1.7	3	1.0–7.0
	Stairs	2.9 \pm 1.1	2	1.0–7.0
	Communication	8.1 \pm 3.8	8	2.0–14.0
	Comprehension	4.2 \pm 1.9	4	1.0–7.0
	Expression	3.9 \pm 2.0	4	1.0–7.0
	Social cognition	10.1 \pm 5.8	9	3.0–21.0
	Social interaction	3.3 \pm 1.9	3	1.0–7.0
	Problem solving	3.3 \pm 1.9	3	1.0–7.0
	Memory	3.5 \pm 1.9	3	1.0–7.0
Barthel Index	Motor Skills*	42.6 \pm 21.7	40.5	13.0–91.0
	Cognitive Skills**	18.3 \pm 9.4	18	5.0–35.0
	Total***	61.0 \pm 30.0	59	18.0–126.0
	Total Score	42.6 \pm 28.3	40	0.0–100.0

*Includes self-care, sphincter control, mobility, and locomotion subgroups.

**Includes communication and social cognition subgroups.

***Includes the main sections FIM Motor Skills and FIM Cognitive Skills.

Table 2. Socio-demographic characteristics of caregivers (N = 100).

Socio-demographic characteristics		n	%
Age (Mean \pm SD = 50.5 ± 12.7 , Min = 18.0, Max = 74.0)	18–49 50 or over	45 55	45.0 55.0
Sex	Female Male	68 32	68.0 32.0
Marital status	Married Single	80 20	80.0 20.0
Have children	Yes No	83 17	83.0 17.0
Education	Elementary school or below Middle school or above	49 51	49.0 51.0
Employment	Employed Not employed	35 65	35.0 65.0
Income	Income $<$ Expense Income \geq Expense	21 79	21.0 79.0
Relationship to the patient	Related Not related	99 1	99.0 1.0
Co-residence with the patient	Yes No	73 27	73.0 27.0

Table 3. Mean scores of the caregivers on SF-36 Quality of Life Scale and Caregiver Burden Scale (N = 100).

Measure	Sub-dimensions	Mean \pm SD	Median	Min–Max
SF-36 Quality of Life Scale	Emotional role functioning	46.7 ± 44.4	33.3	0.0–100.0
	Physical role functioning	46.7 ± 44.4	50	0.0–100.0
	Vitality	46.9 ± 22.6	45	5.0–100.0
	General health perceptions	51.7 ± 22.7	52	5.0–100.0
	Mental health	53.8 ± 19.1	52	12.0–96.0
	Bodily pain	56.5 ± 26.2	52	0.0–100.0
	Social role functioning	60.2 ± 20.8	62.5	12.5–100.0
	Physical functioning	70.4 ± 29.9	77.5	0.0–100.0
Caregiver Burden Scale		n		%
	Little or no burden (0–20 pts.)	12		12
	Mild to moderate burden (21–40 pts.)	38		38
	Moderate to severe burden (41–60 pts.)	6		6
	Severe burden (61–88 pts.)	44		44
		Mean \pm SD	Median	Min–Max
	Total score	39.2 ± 13.8	40.5	13.0–80.0

A significant positive correlation was found between the total FIM scores of the patients and the SF36-QLS general health perception subscale scores of their caregivers ($r = 0.222$, $p = 0.026$). A significant negative correlation was found between the total FIM and BI scores of the patients and the CBS scores of their caregivers (Table 4).

Table 4. The correlation between the SF36-QLS and CBS scores of caregivers and the FIM and BI scores of stroke survivors (N = 200).

Variables	SF36-QLS								CBS
	Emotional role functioning	Physical role functioning	Vitality	General health perceptions	Mental health	Bodily pain	Social role functioning	Physical functioning	
FIM*									
<i>r</i>	0.152	0.148	0.045	0.222	0.151	0.148	0.076	0.187	-0.278
<i>p</i>	0.132	0.142	0.655	0.026	0.134	0.142	0.452	0.063	0.005
BI									
<i>r</i>	0.182	0.170	0.084	0.181	0.135	0.169	0.067	0.140	-0.232
<i>p</i>	0.070	0.091	0.408	0.072	0.180	0.092	0.510	0.164	0.020

* SF36-QLS: SF-36 Quality of Life Scale, CBS: Caregiver Burden Scale, FIM: Functional Independence Measure, BI: Barthel Index.

Selected socio-demographic characteristics of the caregivers were also compared with their mean SF36-QLS and CBS scores. A negative relationship was found between the age of caregivers and their scores on the general health perception ($r = -0.305$, $p = 0.002$) and bodily pain ($r = -0.214$, $p = 0.033$) subscales of the SF36-QLS. Female caregivers had significantly lower scores than their male counterparts on the physical role function ($z = -2.004$, $p = 0.045$), vitality ($z = -2.279$, $p = 0.023$), general health ($t = -2.425$, $p = 0.017$), bodily pain ($z = 2.137$, $p = 0.033$), and social function ($z = -2.999$, $p = 0.003$) subscales of the SF36-QLS. The caregivers with secondary education or above had significantly higher scores than those with primary education or below on all subscales of the SF36-QLS including the emotional role function ($z = -2.203$, $p = 0.028$), physical role function ($z = -2.640$, $p = 0.008$), vitality ($z = -2.843$, $p = 0.004$), general health ($t = -3.085$, $p = 0.003$), mental health ($t = -2.631$, $p = 0.010$), bodily pain ($z = -2.436$, $p = 0.015$), social function ($z = -2.336$, $p = 0.019$), and physical function ($z = -2.063$, $p = 0.039$). The caregivers with secondary education or above had higher average CBS scores than those with primary education or below ($t = 3.731$, $p = 0.000$).

The working caregivers had significantly higher scores than nonworking caregivers on the emotional role function ($z = -2.207$, $p = 0.027$), physical role function ($z = -2.978$, $p = 0.003$), general health ($t = 3.945$, $p = 0.000$), bodily pain ($z = 2.228$, $p = 0.026$), and physical function ($z = -2.259$, $p = 0.024$) subscales of the SF36-QLS. The caregivers who had lower income than their expenses had significantly higher average scores on the mental health subscale of the SF36-QLS ($t = 2.207$, $p = 0.030$) compared with those who had higher income than their expenses.

The caregivers with experience had significantly lower average scores than those without experience on the physical role function ($z = -1.560$, $p = 0.047$) and bodily pain ($z = -2.401$, $p = 0.016$) subscales. However, experienced caregivers were found to have significantly higher average scores on the general health perception subscale ($t = -2.551$, $p = 0.012$) than the inexperienced ones. The caregivers who had received training for caregiving were found to have significantly

higher scores on the general health ($t = 2.303, p = 0.023$) and mental health ($t = 2.615, p = 0.010$) subscales compared with those who had not received training.

A negative correlation was found between the length of caregiving and the scores of caregivers on the physical role function ($r = -0.199, p = 0.047$), general health perception ($p = -0.230, r = 0.022$), and bodily pain ($r = -0.235, p = 0.019$) subscales of the SF36-QLS.

4. Discussion

4.1. Discussion of the findings related to stroke survivors

The mean total FIM score of the stroke survivors was 61.0 ± 30.0 ; they were completely dependent in bathing, lower-body dressing, toileting, and stair climbing and partially dependent in the domains of eating, grooming, upper-body dressing, bladder and bowel management, bed, chair, wheelchair, tub, shower, walk or wheelchair, comprehension, expression, social interaction, problem solving, memory. In previous studies, mean FIM scores in stroke survivors ranged from 67.00 ± 26.20 to 78.1 ± 24.7 [18–21]. The mean FIM score in our study was lower, which indicate worse functional status than those in other studies on stroke survivors. Judging by the BI scores, the functional status of the patients in our study indicated severe dependence. Previous studies utilizing the BI also reported severe or total dependence in stroke survivors [22,23].

4.2. Discussion of the findings related to caregivers for stroke survivors

The emotional role functioning and the physical role functioning ranked lowest and the physical functioning ranked highest among the dimensions of the quality of life of the caregivers for stroke survivors. In a study by Morimoto et al. [24], the caregivers for stroke survivors scored lowest in the general health perceptions domain of the quality of life scale and, similar to our findings, the highest in bodily pain, physical functioning, and social role functioning domains. In their study of the caregivers for stroke survivors, McPherson et al. [25] found that the average scores of caregivers were lower than those of the general population in all domains of the quality of life scale. A majority of the stroke survivors require long-term care since their functional status are significantly affected and they become dependent; this leads to many physical, psychological, social and economical problems for caregivers, affecting their quality of life adversely [10]. Accordingly, our study demonstrated that the caregivers' quality of life was significantly affected.

Sudden onset and long-term effects of stroke may cause temporary or permanent changes in the roles and responsibilities of the caregivers and negatively affect their quality of life [24]. Almost half (44.0%) of the caregivers for stroke survivors reported severe burden with a mean CBS score of 39.2 ± 13.8 . Previous studies reported lower CBS scores (ranging from 27.2 to 33.02) and lower rates of severe burden (26.6%) [26,27]. White et al. [28] evaluated the caregiving burden in the caregivers for stroke survivors during the first and second years of the illness and reported CBS scores of 24.0 ± 16.1 and 26.1 ± 19.9 at the end of the first and the second years, respectively. Thus, the CBS scores of the caregivers in our study were higher than those in previous studies.

A significant relationship was found between the FIM scores of the stroke survivors and their caregivers' average scores from the general health perceptions subscale in CBS. Thus, the general health perceptions of their caregivers are negatively affected as the functional status of the stroke

survivors deteriorates. Previously, Bethoux et al. [29] also demonstrated that the total FIM score of the patients was related to the quality of life of the caregivers.

Significant correlations were found between the FIM and BI scores of the stroke survivors and the CBS scores of their caregivers; the care burden of caregivers increases as the functional status of stroke survivors deteriorates. Other studies have also reported significant negative correlation between the BI scores of the patients and the CBS scores of the caregivers [23,30]. Jönsson et al. [31] reported that the patients' functional status based on their BI scores had positive correlation with the social role functioning, mental health, and bodily pain domains of the quality of life of the caregivers. Better functional status of the patients was suggested to affect the quality of life of the caregivers positively [22]. It is assumed that the caregivers' care-related responsibilities and the time they allocate for patient care increase as the functional status of patient deteriorates and this, in turn, affects the caregiver burden negatively.

The caregivers' scores on the general health perceptions and bodily pain domains of the quality of life scale decreased as caregivers' age increased. It was assumed that the increasing incidence of physical and mental ailments with age negatively affects the quality of life of caregivers. McCullagh et al. [10] also demonstrated a negative relationship between the age and quality of life of caregivers. McPherson et al. [25] reported that there is a strong relationship between the age of caregivers and their quality of life. On the contrary, Akosile et al. [32] found that the physical functioning and physical role functioning domains of the quality of life in younger caregivers were affected significantly more adversely compared with the other groups.

The female caregivers scored, on average, significantly lower than the males in the physical role functioning, vitality, general health perceptions, bodily pain, and social role functioning domains of the quality of life. White et al. [28] have shown that the female caregivers scored significantly lower than the males in the social role functioning, vitality, and mental health domains of the quality of life. This was attributed to the fact that women assume the caregiver role for a longer period of time than men and that women often play a role in the personal care of the patient but men play a role in providing financial support [33].

The caregivers' education level was found to affect all domains of the quality of life. Carod-Artal et al. [27] also demonstrated a relationship between the caregivers' educational status and their quality of life. This was explained by the ability of the caregivers with a higher level of education to better manage the health-related problems and the difficulties experienced during the caregiving [33].

The working caregivers scored, on average, higher than their non-working counterparts in the emotional role functioning, physical role functioning, general health perceptions, and physical functioning domains of the quality of life. This was explained by the increased financial responsibilities of caregivers to support the patient and the ability of working caregivers to manage this situation better [30]. Kalav [30] reported that the majority of the caregivers did not work (83%) and their average scores of quality of life was lower than those who did work albeit there was no significant difference between the groups.

The income status of the caregivers affected the mental health domain of their quality of life. However, Kalav [30] reported that caregivers' income status did not affect their quality of life.

The caregivers with previous caregiving experience were found to score, on average, lower in the physical role functioning and bodily pain domains of the quality of life scale in comparison to their counterparts with no experience. The experienced caregivers were found, however, to score

higher in the general health perceptions domain of the quality of life scale in comparison to those with no experience. Kalav [30] reported higher the quality of life scores for the inexperienced caregivers but the difference was not statistically significant.

Caregivers' caregiving-related training status affected the general health perceptions and mental health domains of the quality of life. McCullagh et al. [10] demonstrated a positive relationship between the caregivers' caregiving-related training status and their quality of life. Accordingly, it was suggested that the caregivers with caregiving-related training had the necessary knowledge and skills to carry out the caregiver role and can cope with the stress, which effectively increases their quality of life.

The caregivers with secondary education or above perceived a higher level of care burden compared with those with elementary education or less. This may be explained by the separation of an educated individual from their work environment, allocation of their time to the care of the patient, and related financial and psychosocial problems. Previous studies reported divergent results regarding the effect of caregivers' educational status on the caregiving burden. While Morais et al. [7] and Yıldırım et al. [34] reported no relationship between educational status and caregiving burden, Reimer et al. [35] reported a higher caregiving burden for the caregivers with elementary education.

There was a significant negative relationship between the length of caregiving and the caregivers' scores on physical role functioning, general health perceptions, and bodily pain domains of the quality of life. Accordingly, as the length of caregiving increases, caregivers' scores on the physical role functioning, general health perceptions, and bodily pain domains of the quality of life decrease [8]. On the contrary, Kalav [30] found no relationship between the length of caregiving and the quality of life of the caregivers.

5. Conclusion and recommendations

The stroke survivors had severe dependency based on their FIM and BI scores. The quality of life of caregivers was moderate or above in the domains of physical functioning, social role functioning, mental health, bodily pain, and general health perceptions and below moderate in the domains of physical role functioning, emotional role functioning, and vitality. Almost half of the caregivers have severe caregiving burden. Caregivers' age, gender, educational status, working status, income status, caregiving experience and training, and the length of caregiving period are important parameters affecting their quality of life. Their educational status is an important parameter affecting the caregiving burden.

Based on the results obtained in this study, nurses are recommended to evaluate the functional status of stroke survivors since it is related to the caregiver burden, to refer the patients to physiotherapy and rehabilitation centers in order to improve the patients' functional status, to advise patients and caregivers about products and services that will facilitate the caregivers' work, to include the caregivers in the care plan, and to prepare the caregivers for the home-care of the patient from the diagnosis stage to the time of discharge. In addition, nurses are recommended to evaluate the caregivers for stroke survivors in terms of the quality of life and the risk factors that affect caregiving burden, to refer them to social support resources that will help them cope with the physical and psychosocial problems during the lengthy periods of care, and to train caregivers about the care-related methods and the skills that facilitate the patient's daily life activities.

Conflict of interest

All authors declare no conflicts of interest in this paper.

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