Caregiving burden and its determinants in Polish caregivers of stroke survivors

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Abstract

Introduction: Despite the growing body of literature on the consequences of providing non-professional care to stroke survivors, the determinants of caregiving burden are still not fully recognized. Identification of significant determinants can facilitate caregiver intervention programs. The aim of this study was to evaluate the level of burden borne by caregivers of stroke patients and to identify the most important determinants of burden at 6 months after hospitalization.
Material and methods: Data were collected from 150 pairs of stroke patients/caregivers. Caregiver burden was assessed on the Caregiver Burden scale (CB). Several characteristics were measured as potential predictors of the burden. Special attention was paid to the caregiver's sense of coherence (SOC) and anxiety. Regression analysis was employed to test the hypothesized relationships between these variables and the burden.
Results: Forty-seven percentage of the caregivers reported a substantial burden (severe or moderate). Caregiver SOC ($p < 0.001$), anxiety ($p < 0.001$) and the patients' functional status ($p < 0.001$) were the most important predictors of the overall burden and the most consistent predictors of the majority of aspects included in the CB scale. Caregiver health, patient's gender, time spent caregiving and social support were also factors related to the burden. The identified predictors explained 67% of the variance in the overall burden.
Conclusions: Clinicians and other professionals should focus on the coping abilities of caregivers, their emotional state and the level of patients' dependency, as these are the vital and modifiable factors affecting caregiver burden following stroke.

Key words: stroke, family caregiving, stress, coping.

Introduction

Despite advances in the treatment of the acute phase, stroke remains a leading cause of death and long-term disability among adults around the world [1–3]. As a disease of an ageing society, the global prevalence of stroke survivors will increase, reaching an estimated 77 million by 2030 [4]. According to the World Health Organization, about 15 million people suffer from a stroke annually, of whom 1/3 die, and another 1/3 are left permanently disabled [5]. In Poland approximately 60,000 people suffer from a stroke each year, that is 0.16% of the general population

[6]. Most stroke survivors return home immediately after discharge from hospital, and their care is taken over by the family or other close people. More than half of the patients experience various impairments and disabilities [7, 8].

Caring for stroke patients, especially disabled ones, may be a source of chronic stress due to the gap between caregiving demands and the physical, psychological and financial resources of the caregivers, all of which may lead to the serious negative consequences referred to in the literature as "caregiving strain" or "burden" [9, 10]. Previous studies have shown that, on average, the caregiver burden following stroke is moderate. In most reports the mean scores in various measurements did not exceed the 50th percentile in their theoretical scope [11–15]. Nevertheless, the percentage of persons experiencing substantial strain in the first year after stroke was estimated at 25% to 54% [16]. The variability of the level of burden depends on a variety of factors related to both the patient's and the caregiver's characteristics. Among the most frequently identified factors are: the patient's functional status [11, 12, 17–21], the caregiver's depressive symptoms [13, 18, 20], the time spent caregiving or the number of caregiving tasks [12, 18, 21] and the caregiver's social support [13, 22]. In the majority of reports the proportion of explained variance in burden (R^2) did not exceed 0.5 [13, 18, 20]. This indicates that there is a place for identifying other significant determinants which should be considered when developing strategies to alleviate caregiver problems. Two such factors that have rarely been taken into consideration are caregiver sense of coherence (SOC) and anxiety.

Antonovsky defined SOC as an individual's ability to cope successfully and confidently with stress through mobilizing all the appropriate internal and external resources [23]. In this context it may be assumed that SOC is an important positive predictor of the burden. To our knowledge there are only two reports [24, 25] from the same large ongoing study that focused specifically on the relationships between SOC as an explanatory variable and caregiver burden after stroke as an outcome variable. The authors concluded that a strong SOC plays a protective role against the burden. In addition, several studies concerning associations between the caregivers' SOC and concepts similar to burden, such as quality of life, well-being, burn-out and mental health, have been published [26–29].

Anxiety is a physiological reaction to stress. However it can be harmful when it becomes prolonged. Prevalence of anxiety among carers of stroke patients has been reported as high (up to 58%) [30] and, according to some authors, it is higher than depression [31–33]. Nevertheless, few studies have focused on the association between burden of care and anxiety symptoms, and these have shown that anxiety is an independent factor affecting the burden within the first year after stroke [13, 20]. Most of the research on caregiving following stroke has been conducted in western Europe or in the USA [16, 34]. This is the first such study carried out in Poland.

The general aim of the study was to better understand the caregiver burden during the first months after discharge from hospital. The specific aims were: (1) to evaluate the severity of burden experienced by caregivers, (2) to identify the best predictors of caregiver burden from the characteristics of the patients, and (3) to identify the best predictors of caregiver burden from the characteristics of the caregivers, focusing especially on the sense of coherence and emotional status.

Material and methods

Design and procedure

The present work is part of a larger project conducted in our research departments which examines caregiving for individuals following a stroke [35, 36]. We used a non-experimental prospective, cross-sectional design in which the participants were assessed at 2 different time points: time 1, during the patients' hospitalization, and time 2, 6 months after discharge. This design allowed us to measure and describe the burden, in terms of subjective and multidimensional phenomena, as well as to gather simultaneously data on several explanatory variables which might be important from the clinical stand point. The 6 months' time frame was selected because the functional status of stroke patients usually stabilizes within the first 6 months following the stroke, which simultaneously is the most difficult time for caregivers [37].

During the first examination, the socio-demographic characteristics of the patients and their caregivers, as well as data on the background medical and clinical status of the patients, were collected. During the second assessment, data on caregiver burden and its potential predictors, as well as on the patients' neurological and functional status, were gathered. The second assessment was performed at the participants' home. All the participants gave their voluntary informed consent. The study was approved by the Poznan Bioethics Committee of the University of Medical Sciences.

Study sample

The study participants were patient/primary caregiver pairs consecutively admitted to the Neurological Department of Wielkopolska Province Hospital in Poznan, Poland. This is a multi-profile hospital providing specialist comprehensive

inpatient medical service to the inhabitants of Wielkopolska, a geographical region situated in the north-west of Poland with a population of approximately three and a half million [38]. The population of Wielkopolska, as with the country as a whole, is homogeneous in race and ethnicity; 97% of people are of Polish nationality.

Inclusion criteria for the patients were: age above 18 years and a diagnosis of first-ever stroke. The exclusion criteria were: recurrent stroke, presence of an additional illness and/or prestroke disability which required persistent patient help, alcohol or drug dependence, functional recovery before hospital discharge (Barthel Index > 14 points), and discharge to an institution other than home. The final sample consisted of 80 men and 70 women, all of Polish origin, with a mean age of 64 years (standard deviation, SD = 12.7), median = 63 (range: 21–95). The women were significantly older than the men: median = 71 years vs. 59 years, $p < 0.001$. Inclusion criteria for the caregivers were: being a spouse/partner, parent, adult child, other significant family member or friend who lived with the patient or was in close contact several times per week, directly involved in the patient's care, and lacking previous experience in providing care for a chronically ill family member. The exclusion criterion was: being a professional or paid caregiver. The final sample consisted of 124 women and 26 men, all of Polish origin, with a mean age of 53.5 years (SD = 13.8); median 55 (range: 18–85). No significant difference in age between male and female caregivers was found. Detailed characteristics are shown in Table I.

Measurement tools

Assessment of caregivers

The Caregiver Burden scale (CB) was used to assess the burden. This scale consists of 22 items which can be separated into five subscales [39]. The range of scores was from 1 to 4. A score of 1.00–1.99 indicated a low burden, 2.00–2.99 a moderate and 3.00–4.00 a high burden. Our study was the first to use the CB scale in Poland. The English version of the instrument provided by Sölve Elmståhl was translated into Polish by two native Polish experts in the English language, and then back-translated into English by another two native Polish language experts. An expert committee was involved in reaching final agreement on both translations. The Cronbach's α reliability coefficient for the scale used in the current study was 0.9, which was similar to that for the original instrument (Cronbach's α 0.9) [39].

The Hospital Anxiety and Depression Scale (HADS) was used to detect depression and anxiety [40]. A score of 11 or more on the HADS-Anxiety

Table I. Socio-demographic characteristics of the caregivers

Characteristics	Number	Percentage
Gender:		
Male	26	17.0
Female	124	83.0
Age, mean (SD) [years]	53.51 (13.85)	
Relationship:		
Spouse	86	57.0
Child	38	25.0
Sibling	7	5.0
Parents	3	2.0
Distant relatives or friend	16	11.0
Education:		
Primary	30	20.0
Vocational	49	33.0
Secondary school	52	34.0
University	19	13.0
Working status:		
Active	55	36.7
Non-active	95	63.3
Living arrangement status:		
Living with the patient only	44	29.0
Living with the patient and/or with others	106	71.0
Time providing care daily, mean (SD) [h]	8.32 (6.10)	

SD – standard deviation

and HADS-Depression subscales denoted anxiety or depression. Antonovsky's Sense of Coherence scale (SOC-29) was used to measure the carers' global life orientation [23]. The possible total score ranged from 29 to 203 and, for descriptive purposes, it was divided by tertiles into weak (29–87), moderate (88–145) and strong (146–203). The Berlin Social Support Scale (BSSS) was used to assess the amount of emotional, informational and instrumental support received by the caregivers [41]. Total scores ranged from 15 to 60. One single item of the World Health Organization Quality of Life-BREF (WHOQOL-BREF) was applied to assess an overall perception of health, namely "How satisfied are you with your health?" Responses were rated on a 5-point Likert scale [42]. A structured questionnaire was used to gather the clinical data of the patients and the socio-demographic data of both the patients and the caregivers.

Assessment of patients

The Scandinavian Stroke Scale (SSS) and the Barthel Index (BI) were used to assess the neurological and functional status, respectively. These tools are popular instruments in neurology with well-established psychometric properties [43, 44].

The Dynamic Assessment of Aphasia Scale was applied to assess the communicative ability of the patients [45]. The short form of the Geriatric Depression Scale (GDS) was used as a screening measure of depressive symptoms. This scale was originally established for people more than 55 years old, but it has also been used in younger in-dividuals while retaining satisfactory psychometric properties [25, 46, 47].

Statistical analysis

Descriptive statistics of the variables are presented as percentages, mean, median and standard deviation (SD). Changes in the neurological and functional status of the stroke patients were assessed by the Wilcoxon test and McNemar's tests. Bivariate analyses were applied to assess relationships between caregiver burden and patient/caregiver characteristics and to select variables for inclusion in the multivariate analyses (Table II). Pearson's *r* correlation coefficient was used to

Table II. Candidate predictor variables for caregiver's burden. Bivariate analysis ($p \leq 0.10$)

Characteristics	Burden total	General strain	Disappoint-ment	Emotional involvement	Isolation	Environment
Patient:						
Gender (median: male vs. female)[b]	2.02 vs. 1.77	2.25 vs. 2.0	2.40 vs. 1.80	1.66 vs. 1.33	NS	NS
Age[a]	NS	0.17	NS	NS	0.20	NS
SSS[a]	−0.47	−0.48	−0.44	NS	−0.37	−0.24
BI[a]	−0.55	−0.54	−0.41	−0.19	−0.45	−0.37
Depression (median: yes vs. no)[b]	2.0 vs. 1.81	2.12 vs. 2.0	2.20 vs. 2.0	1.66 vs. 1.33	NS	1.66 vs. 1.33
Speaking difficulties (median: yes vs. no)[b]	NS	NS	2.60 vs. 2.0	NS	NS	NS
Caregiver:						
Age[a]	0.17	0.16	0.16	NS	0.19	NS
Relationship (median: spouses vs. not spouses)[b]	2.0 vs. 1.79	NS	2.40 vs. 1.80	NS	NS	NS
Living arrangement (median: living with the patient only vs. other living arrangement)[b]	2.09 vs. 1.86	2.37 vs. 2.0	2.40 vs. 2.10	NS	2.16 vs. 1.66	NS
Working status (median: active vs. not active)[b]	1.86 vs. 1.95	1.87 vs. 2.25	2.0 vs. 2.20	NS	NS	NS
Presence of diseases (median: yes vs. no)[b]	2.05 vs. 1.72	2.37 vs. 1.81	2.20 vs. 2.0	NS	2.0 vs. 1.33	NS
Self-assessment of health[a]	−0.35	−0.38	−0.32	−0.31	−0.20	NS
HADS-anxiety[a]	0.60	0.55	0.53	0.39	0.47	0.21
HADS-depression[a]	0.57	0.54	0.48	0.44	0.43	0.19
BSSS[a]	−0.26	−0.25	−0.18	−0.30	−0.23	NS
SOC-29[a]	−0.65	−0.56	−0.57	−0.53	−0.47	−0.29
Hours spent helping per day	0.38	0.36	0.38	0.18	0.18	0.24

[a]*Pearson correlation coefficient,* [b]*Mann-Whitney U test. NS – nonsignificant, SD – standard deviation, SSS – Scandinavian Stroke Scale, BI – Barthel Index, HADS – Hospital Anxiety and Depression Scale, BSSS – Berlin Social Support Scale, SOC – Sense of Coherence Scale*

analyze relationships between burden and continuous variables. Taking into account the skewness, the results were additionally checked with the Spearman rank correlation coefficient. Both measures showed similar results. Correlation coefficient values were considered as small, medium or large, expressing weak, moderate and strong relationships when their values were below 0.3, from 0.3 to 0.49, and 0.5 and above, respectively. It should be noted that a weak relationship means that the analyzed variables share a small amount of variance and, because of that, despite their statistical relevance, their practical significance might be relatively weak [48].

The Mann-Whitney U test was used to examine the relationships between burden and dichotomous variables. Stepwise multiple regression analysis was used to identify independent predictors of burden, taking into account the total CB and its five indices (subscales) scores as dependent variables. Since the sample size was 150, and there was a large number of potential explanatory variables, we entered in the regression analysis those patient/caregiver characteristics that were significantly correlated with at least one subscale in the bivariate analysis ($p < 0.10$).

Residual analyses and collinearity diagnostics were carried out to verify the basic assumptions of the regression. If necessary, a logarithmic transformation of the dependent variable was performed. The analyses were conducted with Statistica StatSoft 9 software (StatSoft Polska, Kraków, Poland).

Results

Patients' clinical characteristics

At 6 months after stroke, most patients had improved significantly in their neurological and functional status. However, 8% of the patients still presented severe stroke impairment and 15% demonstrated very severe or severe functional dependence. Depressive symptoms were present in 43% of the subjects (Table III). There were no significant differences in neurological status, functional status or depression level between men and women. Also, no significant correlations were observed between age and neurological status and depression. Only a weak relationship was found for age and functional status at time 2 ($r = -0.21$; $p < 0.05$).

Caregivers' characteristics and burden

The mean HADS-Depression and HADS-Anxiety scores were relatively low. However, one fifth of the caregivers had depressive symptoms, and one third had symptoms of anxiety. The mean SOC-29 value indicates that, on average, the caregiver's SOC was moderate. The BSSS mean score demonstrates

Table III. Clinical characteristics of the stroke patients at discharge and after 6 months

Characteristics	Discharge	6-month follow-up	Value of p
Neurological status (SSS):			
Mean (SD) (range 0–58 bad–good)	29.33 (11.15)	46.13 (10.35)	–
Median	30.0	48.0	< 0.001[a]
Very severe/severe impairment (range: 0–29), n (%)	73 (49.0)	12 (8.0)	–
Moderate/mild impairment (range: 30–58), n (%)	77 (51.0)	138 (92.0)	–
Functional status (BI):			
Mean (SD) (range 0–20/bad–good)	4.33 (4.11)	14.73 (5.45)	–
Median	2.0	16.0	< 0.001[a]
Very severe/severe disability (range: 0–9), n (%)	129 (86.0)	23 (15.0)	–
Moderate/mild disability (range: 10–20), n (%)	21 (14.0)	127 (85.0)	–
Depressive mood (GDS)*:			
Yes (range: 2–4), n (%)	–	65 (43.0)	–
No (range: 0–1), n (%)	–	85 (57.0)	–
Speaking difficulties:			
Yes – n (%) (range: 0–8)	43 (29.0)	41 (27.0)	0.479[b]
No – n (%) (> 8)	107 (71.0)	109 (73.0)	

*GDS assessed at 6 months only, [a]Wilcoxon test, [b]McNemar's test, SSS – Scandinavian Stroke Scale, SD – standard deviation, BI – Barthel Index, GDS – Geriatric Depression Scale

that, on average, caregivers received high social support. The mean WHOQOL score reflects moderate satisfaction with their own health (Table IV). The mean total CB score was 2.08 (SD = 0.6). Nearly half of the caregivers experienced a moderate or severe burden. The highest burden was noted in General strain and Disappointment, the lowest in the Environmental subscale (Table V).

There were no significant differences in SOC, BSSS, HADS-Depression/Anxiety, or WHOQOL between men and women. Also there were no significant correlations of those variables with age, except for a weak relationship of age with HADS-Depression ($r = 0.24$; $p < 0.05$) and WHOQOL ($r = -0.24$; $p < 0.05$).

Association between patient/caregiver characteristics and the caregivers' total and subscale burden scores

Variables that were significantly related to the CB scores ($p \leq 0.10$) are displayed in Table II. There were 5 patient and eleven caregiver characteristics that were associated with the total score and/ or at least with one subscale. Strong correlations with the total score were observed for SOC, caregiver anxiety, depression, and patient's functional status. Moderate correlations were seen for the patient's neurological status and for time spent caregiving. Weak correlations were noted for caregiver social support and age. A similar distribution of the coefficient levels was found in the subscales, although the strength of the relationships was generally weaker. Additional analyses showed significant correlations between SOC and anxiety ($r = 0.63$, $p < 0.001$), SOC and depression ($r = 0.62$, $p < 0.001$) and between SOC and social support ($r = -0.43$, $p < 0.001$).

The significant correlates of the caregiver burden were selected to identify their unique contributions to regression models. Stroke impairment was not included because of its high correlation (collinearity) with functional disability ($r = 0.81$). The caregiver's SOC and anxiety and the patient's functional status were found to be the strongest predictors of the total burden, which explained 67% of its variance, together with the patient's gender and the caregiver's morbidity. The three aforementioned variables were also predictors for three out of four CB subscales. Together with the other seven variables, they explained 35–60% of the variance in the CB subscales (Table VI). Environment was not used in the analysis because the residuals were not normally distributed and a log transformation was not effective.

Discussion

Stroke not only has direct consequences in the form of physical and psychological impairment of the patient, but also results in a burden for the caregivers, which may constitute a significant health concern reducing the quality of care provided to the loved ones [9, 10]. The findings reported here provide evidence that caregiver strain is a multidimensional phenomenon, influenced both by factors on the part of the patient as well as on the part of the caregiver. This indicates the need for professional intervention aimed at both improving post-hospital stroke outcomes and improving caregiver's well-being.

The first specific aim of our study was to evaluate the severity of burden borne by caregivers of stroke patients. The results showed that almost one half of the caregivers (47%) experienced significant strain. In comparison with similar Europe-

Table IV. Means and standard deviations on self-reported variables for stroke caregivers

Scales	Mean (SD)
Hospital Anxiety and Depression Scale:	
Depression subscale (range: 0–21/good–bad)	5.51 (4.90)
Score ≥ 11, n (%)	27 (18.0)
Anxiety subscale (range: 0–21/good–bad)	8.57 (4.71)
Score ≥ 11, n (%)	49 (33.0)
Sense of Coherence Scale (range: 29–203/bad–good)	141.06 (26.99)
Berlin Social Support Scale (range: 15–60/bad–good)	50.83 (12.85)
Self-assessment of health (range 1–5/bad-good)	3.41 (0.96)

SD – standard deviation

Table V. Caregiver Burden scale scores in stroke caregivers

CB scale (total and subscale score range 0–4/good–bad)	Result
Total burden, mean (SD):	2.08 (0.65)
Low burden, n (%)	80 (53.0)
Moderate burden, n (%)	52 (35.0)
Severe burden, n (%)	18 (12.0)
General strain, mean (SD)	2.27 (0.81)
Disappointment, mean (SD)	2.28 (0.84)
Emotional involvement, mean (SD)	1.68 (0.85)
Isolation, mean (SD)	1.92 (0.93)
Environment, mean (SD)	1.79 (0.78)

CB – Caregiver Burden scale, SD – standard deviation

Table VI. Predictors of caregiver's burden. Multiple regression analysis ($p \leq 0.05$)

Burden	Predictors	Stand. β	Value of t	Value of p	Adj. R^2
Total score	Sense of coherence	−0.43	−7.04	< 0.001	0.67
	Functional status	−0.35	−6.98	< 0.001	
	Anxiety	0.23	3.72	< 0.001	
	Patients' gender (male)	0.14	2.84	0.005	
	Presence of diseases (yes)	0.12	2.47	0.015	
General strain	Functional status	−0.38	−6.93	< 0.001	0.60
	Sense of coherence	−0.28	−4.13	< 0.001	
	Anxiety	0.24	3.52	0.001	
	Presence of diseases (yes)	0.16	2.90	0.004	
	Health self-assessment	−0.15	−2.59	0.010	
Disappointment	Sense of coherence	−0.38	−5.03	< 0.001	0.56
	Patients' gender (male)	0.23	3.94	< 0.001	
	Hours spent helping per day	0.20	3.09	0.002	
	Anxiety	0.19	2.65	0.009	
	Functional status	−0.18	−2.69	0.008	
	Patients' age	−0.14	−2.36	0.02	
Emotional involvement*	Sense of coherence	−0.49	−6.86	< 0.001	0.35
	Health self-assessment	−0.15	−2.11	0.036	
	Patients' gender (male)	0.14	2.08	0.039	
Isolation	Anxiety	0.37	5.75	< 0.001	0.41
	Functional status	−0.34	−5.06	< 0.001	
	Social support	−0.16	−2.33	0.021	
	Living arrangement (with the patient only)	0.14	2.06	0.041	

*Stand. β – standardized β, Adj. R^2 – Adjusted R^2. *The emotional involvement subscale score was logarithmically transformed.*

an studies carried out at 6 months after stroke, this proportion is relatively high. The relevant figures for Norway, Netherlands, Belgium and Scotland are 25%, 30%, 29%, and 37%, respectively [11, 12, 16, 49]. These discrepancies may reflect, on the one hand, methodological differences between the studies, but may also indicate differences in caregiving support systems in Europe. The EUROFAMCARE study showed that carers' use of support services is generally limited throughout Europe, but in Poland it is noticeably worse than in Germany, Sweden, and the UK. In most western European countries more than 20% of caregivers use a support service, while in Poland fewer than 5% do so [50].

The next aim of this work was to identify independent determinants of caregiver burden in terms of the total CB score and the subscale scores among key factors known from the literature, together with less frequently analyzed variables,

such as caregiver's sense of coherence and anxiety. Our findings show that one of the most important factors that have been strongly correlated and most consistently associated with burden is the sense of coherence. Caregivers with a stronger SOC reported lower levels of burden in the total CB scale and in the majority of subscales controlling for other variables. These findings support Antonovsky's SOC theory and corroborate research by Chumbler *et al.* [24] and van Puymbroeck *et al.* [25] that point to a positive role of SOC in alleviating the sequelae of psychological distress. The results of the correlation analysis concerning SOC in the present study, together with the findings of other investigations based on SOC theory [23, 25, 29, 35], allow us to speculate that the positive effect of SOC on caregiver burden might occur as a protection against depression and anxiety, as well as through mobilizing social support. However, this framework should be further explored in a lon-

gitudinal study, in different phases of the stroke process and caregiving. Nevertheless, our data indicate the need for professional interventions to reduce stress, develop skills to deal with stressful situations and protect or strengthen individual inner coping resources. This type of intervention includes psycho-social programs based on information, learning skills and emotional support, as stressed in a recent review by Garces *et al.* [51].

Another highly important predictor of caregiver burden in this study was anxiety, which was present in a third of the participants. As has been shown in the literature, increased anxiety during the first few months of caregiving may stem from uncertainty about the patient's condition, about leaving the patient alone, fear of the next stroke, and uncertainty about the future [32, 52]. In the wake of this and other authors' results [13, 20, 21], we can conclude that among the two emotional expressions of psychological distress, namely depression and anxiety, the latter seems to be predominant in the first months of caregiving. This hypothesis could partially explain the lack of a significant contribution of depression to the variance of burden. Nevertheless, greater recognition of the emotional state of the caregivers is required. Also, there is a need for more longitudinal studies to investigate co-occurrence and interdependence between anxiety and depression since, as has been shown by Cooper *et al.* [53], interventions taken for depressive symptoms may not automatically reduce anxiety. Moreover, because both depression and anxiety were found to be inversely associated with SOC, there is a need for a further longitudinal investigation of these relationships.

In the current study, patient physical disability was the third most important factor related to the caregiver's burden. This is in line with several previous reports [11, 12, 17–21] and indicates the importance of long-term efforts to foster the patient's physical independence on the one hand, and to teach the caregivers how best to perform basic and instrumental care tasks on the other.

There were other significant determinants of the burden, although they were less consistent within the entire CB scale. One was caregiver health status, operationalized as self-evaluation of health and the presence or absence of diseases. In accordance with our predictions, those in poorer health reported a higher burden. This is in line with similar research by Choi-Kwon *et al.* [18], who found that caregiver self-rated health status was associated with burden score, but only on one out of three sub-domains analyzed. Other less consistent predictors of increased burden in our study were socio-demographic variables, such as the living arrangement (living with the patient

only), younger age of the patient, patient's gender (men) and larger amount of time providing care. Interestingly, providing care for a man was related to higher Total Burden and Disappointment and Emotional involvement scores than caring for a woman. This may be related to loss of income resulting from the man having to give up his job. In the literature, findings about socio-demographic characteristics are highly inconsistent. For example, female caregivers have frequently been seen as more burdened than men [16], but this was not confirmed in our study. Contrary to our expectations, social support was not among the most important determinants of the total burden. However, it did have a predictive value for the Isolation subscale. We can hypothesize that such factors as reciprocity, family conflicts and balance in caregiving between the primary caregiver and other family members may also play a role. In addition, it is possible that the caregivers need more time to fully accept help from others [52].

A few limitations of this research need to be mentioned. First, the study group did not include caregivers of those patients who were in a good functional state before discharge and those who died after discharge. This may limit the representativeness of the sample and therefore the generalisability of the findings. The reasons for including only patients who were moderately or severely affected at the time of discharge was that we had planned the study to capture the experience of caregivers connected with the necessity of providing care in activities of daily living (ADL). Nevertheless, at 6-month follow-up the patients were differentiated according to their functional status.

Second, the cross-sectional and regression-correlation model of the study did not allow us to draw definite conclusions about the cause-effect type of relationship between the burden and its determinants. However, it has been the first stage of our study which is being continued, and we hope that in the longer term, after another follow-up, it will be possible to determine the direction of relationships between the key research variables better.

Third, cognitive and neurobehavioural changes in the stroke patients were not considered in this study although they are frequently observed after stroke and may affect caregivers' well-being [49, 54]. We did not include these factors as our study focused mainly on the role of a caregiver's SOC and emotional status in the presence of other, previously known predictors of the burden. However, further studies evaluating independent relationships between the behavioral and cognitive status of the patients and caregiver strain are needed. Nevertheless, with these limitations in mind, we hope that this study makes a contri-

bution to increasing knowledge on caregiver burden, reinforces the findings of other authors, and sheds some new light on modifiable predictors of the burden, especially on the caregivers' psychological characteristics.

In conclusion, this study showed that a substantial proportion of non-professional caregivers experienced a moderate or severe level of burden. Clinicians and other professionals should focus on the coping abilities of caregivers, their emotional state and their patients' dependency, as these are the vital and modifiable factors affecting the burden of care following stroke. Future research should assess simultaneously the trajectories of post-stroke recovery, psychological distress and the caregiving process, and investigate the significance of both protective and harmful factors at different periods following a stroke.

Acknowledgments

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