Caregiver burden after stroke: towards a structural model

Obciążenie osób sprawujących opiekę nad chorym po udarze mózgu: w kierunku modelu strukturalnego

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Abstract

Background and purpose: Stroke may impose a severe burden on both the patients and their caregivers. Although there is substantial literature relating to the adverse impact of stroke on patients, considerably less is known about its impact on their caregivers. The aim of this study was to analyse predictive factors of the overall burden in caregivers of stroke victims and to verify the structural model of burden, built on the basis of theoretical and empirical assumptions.

Material and methods: One hundred and fifty pairs of patients and their caregivers were evaluated. The Caregiver Burden Scale (CB), Hospital Anxiety and Depression Scale (HADS), Sense of Coherence Scale (SOC), Social Support Scale, Geriatric Depression Scale, Barthel Index and Scandinavian Stroke Scale were all used to evaluate caregiver burden and the characteristics of patients and caregivers.

Results: The caregivers experienced a moderate burden (mean CB = 2.08) and emotional distress (mean total HADS = 14.1). Path analysis showed that higher burden was associated with a lower SOC score, higher emotional distress, and lower patient's functional status. Higher emotional distress, in turn, was associated with lower SOC and lower patient's functional status. These results show that the burden and the degree of emotional disturbance are two distinct negative consequences of caregiving.

Conclusions: The negative consequences of caregiving depend mainly on the caregiver's intra-psychic factors and the patient's disability. Professional interventions should be

Streszczenie

Wstęp i cel pracy: Udar mózgu (UM) niesie ze sobą poważne konsekwencje zarówno dla chorych, jak i dla ich opiekunów. Istnieją liczne badania dotyczące negatywnego wpływu UM na funkcjonowanie i jakość życia pacjentów, zdecydowanie mniej prac poświęcono następstwom udaru mózgu doświadczanym przez opiekunów. Celem niniejszej pracy była analiza czynników predykcyjnych obciążenia u opiekunów chorych po UM i weryfikacja modelu strukturalnego obciążenia skonstruowanego na podstawie założeń teoretycznych i przesłanek empirycznych.

Materiał i metody: Zbadano 150 par chorych po UM i ich opiekunów. Do oceny obciążenia oraz czynników ze strony pacjenta i opiekuna zastosowano: Skalę Oceny Obciążenia (CB), Szpitalną Skalę Lęku i Depresji (HADS), Skalę Poczucia Koherencji (SOC), Skalę Wsparcia Społecznego, Krótką Geriatryczną Skalę Depresji, Wskaźnik Barthel i Skandynawską Skalę Udaru Mózgu.

Wyniki: W badanej grupie opiekunów stwierdzono średni poziom obciążenia [średnia punktacja CB (zakres: 0–4) = 2,08] i nasilenia zaburzeń emocjonalnych [średnia punktacja w HADS (zakres: 0–42) = 14,1]. Analiza ścieżek wykazała, że wyższy poziom obciążenia był związany ze słabszym SOC, większym stopniem zaburzeń emocjonalnych opiekuna i gorszym stanem funkcjonalnym pacjenta. Z kolei gorszy stan emocjonalny opiekuna był powiązany ze słabszym SOC i mniejszą sprawnością chorego. Potwierdzono hipotezę, że obciążenie i zaburzenia stanu emocjonalnego stanowią odręb-

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targeted at enhancing caregivers' ability to cope with stress, improving their caregiving skills and reducing the physical dependence of patients.

Key words: burden, caregiver, stroke.

ne, aczkolwiek powiązane ze sobą niekorzystne następstwa sprawowania opieki.

Wnioski: Negatywne skutki sprawowania opieki nad chorym po UM zależą głównie od czynników wewnątrzpsychicznych ze strony opiekuna i stopnia niepełnosprawności chorego. Działania profesjonalne powinny być ukierunkowane na wzmacnianie zdolności opiekunów do radzenia sobie ze stresem, poprawę ich kompetencji opiekuńczych oraz zwiększenie samodzielności pacjenta.

Słowa kluczowe: obciążenie, opiekun, udar mózgu.

Introduction

Stroke is a leading cause of death and a source of persistent disability in its victims around the world [1-4]. According to Polish authors, one year after a stroke, about 50% of patients are not independent and require constant or temporary care. In the majority of cases (84%) this care is provided by family members [5]. Providing long-term care at home may be a cause of chronic stress, having various negative consequences that are described in the literature as caregiver burden or strain. The burden mainly affects the so-called primary caregivers who, quoting from Lavretsky [6], may be described as 'individuals who provide extraordinary, uncompensated care, predominantly in the home setting, involving significant amounts of time and energy for months or years, and requiring the performance of tasks that may be physically, emotionally, socially, or financially demanding'.

Studies of the caregiver burden of stroke patients show that the percentage of people experiencing a significant burden is 25-54% [7]. The variability in the level of the burden depends on a range of factors associated with both patient and caregiver. The most frequently identified patient characteristics are functional status, neurological deficit and emotional state. The caregiver characteristics include emotional state, health status, time spent providing care, dispositional factors of caregiving, including ability to cope with stress, and social support [8-20]. The less frequently identified determinants are socio-demographic features such as sex, age, type of relationship and profession [7].

Of particular interest among the aforementioned factors are sense of coherence (SOC) and the emotional state of the caregiver. SOC is the central construct of the concept of salutogenesis enunciated by Antonovsky [21]. Generally, this is defined as a global orientation of an individual which is manifested by the extent to which the individual feels that the stimuli from the outside and inside are structured, predictable and understandable, that the person has access to resources which allow him or her to meet the demands posed by these stimuli [21]. Following this definition, and from numerous studies conducted in this field, it may be assumed that SOC serves as both a coping resource and a mediator in the transactional stress process. This factor may therefore have both a direct and an indirect influence on the severity of negative consequences of caregiving, as has also been suggested by Van Puymbroeck *et al*. [18] and Chumbler *et al.* [19]. Emotional state is a variable that has been used in the studies of burden in two ways: either as a predictor of burden or as a separate outcome of caregiving which is parallel to burden [18,22]. Taking into account the probability that, in the light of empirical evidence, both are correct, instead of adopting an alternative approach, a hierarchical approach may be used, including the double role of this factor i.e., as both a predictor and an outcome. Such an approach is not only more complete, but also allows for a simultaneous investigation into predictive factors of both the emotional state of a caregiver as well as of the burden.

The aim of the present study was to analyse predictive factors of the overall burden in caregivers of stroke victims and to verify the structural model of that burden, built on the basis of theoretical assumptions and the findings of previous research. The verification process included checking the following hypotheses: 1) that patient and caregiver characteristics influence the emotional state of the caregiver and the level of burden, 2) that the emotional state of the caregiver affects the level of burden, 3) that the sense of coherence serves as a mediator between the patient and caregiver variables and finally, the burden and emotional state of the caregiver.

Knowledge about the association between these variables may be helpful in understanding the nature of the caregiver burden after stroke better, and could serve as the basis for professional interventions to reduce the personal costs of caregiving. To the best of our knowledge this is the first study in Poland to address the issue of caregiver burden following stroke.

Material and methods

Subjects

The clinical study involved 150 stroke patients and their caregivers consecutively admitted to the acute neurological department between 2005 and 2008. Stroke was defined according to World Health Organization criteria and confirmed by computed tomography. The inclusion criteria for the patients were as follows: a first-ever ischaemic or haemorrhagic stroke, the presence of functional deficit prior to discharge from hospital (Barthel Index, BI ≤14), and full independence in the activities of daily living (ADL) before stroke onset. Patients with other chronic diseases and health problems significantly impairing their physical and/or mental condition were excluded from the study. The final sample comprised 80 (53%) men and 70 (47%) women aged between 21 and 95 (mean 64 years; standard deviation [SD] = 12.7). Their detailed characteristics are presented in Table 1.

The inclusion criteria for the caregivers were as follows: a declaration that the person is the closest caretaker of the patient, a lack of previous experience in providing care for a chronically ill person, not receiving payment for the care and consent to participate in the study. The final carer group consisted of 124 (83%) women and 26 (17%) men aged between 18 and 85 (53.5 years; SD = 13.8). The majority were spouses (57%) and children of the patients (25%), mainly daughters (87%). More than half (59%) of the carers reported suffering from a variety of complaints, of which the most frequent were circulatory disorders (39%), arthritis (26%), endocrinological disorders (11%) and neurological disorders (5%). Detailed characteristics are given in Table 2.

Table 1. Patients' characteristics

Sex	
Male, *n* (%)	80 (53%)
Female, *n* (%)	70 (47%)
Age [years], mean ± SD	64.0 ± 12.6
Education, *n* (%)	
Elementary	49 (33%)
Vocational	52 (34%)
Secondary	40 (27%)
University	9 (6%)
Neurological status, [SSS score, 1-58], mean ± SD	46.1 ± 10
Functional status [BI score, 0-20], mean ± SD	14.7 ± 5.1
Emotional status [GDS score, 1-4], mean ± SD	1.6 ± 1.3

SD – standard deviation, SSS – Scandinavian Stroke Scale, BI – Barthel Index, GDS – Geriatric Depression Scale

Table 2. Caregivers' characteristics

Sex	
Male	26 (17%)
Female	124 (83%)
Age [years], mean ± SD	53.5 ± 13.8
Relationship, *n* (%)	
Spouse	86 (57%)
Child	38 (25%)
Sibling	7 (5%)
Parents	3 (2%)
Distant relatives or non-family member	16 (11%)
Education, mean ± SD	
Primary	30 (20%)
Vocational	49 (33%)
Secondary	52 (34%)
University	19 (13%)
Working status, *n* (%)	
Active	51 (34%)
Non-active	99 (66%)
Length providing care daily [hours], mean ± SD	8.32 ± 6.9
Burden [CB score, 1-4]	
Total score, mean ± SD	2.08 ± 0.6
Low, *n* (%)	80 (53%)
Moderate, *n* (%)	52 (35%)
Severe, *n* (%)	18 (12%)
Sense of coherence [SOC-29 score, 29-203], mean ± SD	141.1 ± 30.0
Emotional status [HADS score], mean ± SD	
Depression [HADS-D, 0-21]	5.5 ± 4.9
Anxiety [HADS-A, 0-21]	8.6 ± 4.7
Total score [HADS total, 0-42]	14.1 ± 8.7
Social support [BSSS score, 15-60], mean ± SD	50.8 ± 12.8

BSSS – Berlin Social Support Scale, CB – Caregiver Burden, HADS – Hospital Anxiety and Depression Scale, SOC – Sense of Coherence

Methods

The patients were examined twice: before their discharge from the acute neurological ward and 6 months later. The neurological, functional and emotional status was assessed. Stroke severity was measured with the *Scandinavian Stroke Scale* (SSS), functional disability with the *Barthel Index* (BI) and emotional status with the *Short Geriatric Depression Scale* (GDS) [23-25].

The caregivers were recruited during the patient's hospitalization and interviewed at 6 months after discharge.

The caregiver burden, emotional state, sense of coherence and social support were evaluated. Caregiver burden was assessed with the Polish version of the *Caregiver Burden Scale* (CB Scale) [26]. This scale includes 22 questions in 5 subscales: general strain, isolation, disappointment, emotional involvement and environment. The range of the total and subscale score is from 1 to 4, with a higher score indicating more severe burden. In this report, only the total score is used. According to the authors of the original CB Scale the following categories of burden are used: low (1.00-1.99), average (2.00-2.99) and high (3.00-4.00). The Cronbach's alpha reliability coefficient for the Polish version of the CB Scale is 0.89.

The screening assessment of emotional status was performed with the *Hospital Anxiety and Depression Scale* (HADS) [27]. This is a 14-item tool with seven questions concerning anxiety (HADS-A) and seven questions concerning depression (HADS-D). Scoring 8 points or more on both of the subscales suggests the presence of depressive symptoms and increased anxiety. A high combined HADS total score (HADS-T) may indicate psychological distress and, as such, was used in the bivariate and multivariate analyses in our study [28].

The sense of coherence was measured with the *Sense of Coherence Questionnaire SOC-29* [29]. The scale here consists of 29 items, measuring three dimensions of SOC: comprehensibility, manageability, and meaningfulness. The total SOC score ranges from 29 to 207. Scoring between 133 and 160 indicates an average level of SOC.

Social support was evaluated with the *Berlin Social Support Scale* (BSSS) [30]. This tool includes 15 items concerning emotional, informational and instrumental support. The range of scores is between 15 and 60. Other patient and caregiver characteristics were gathered by means of a semi-structured questionnaire developed for the purpose of the study.

Statistical analyses

The first stage included statistical descriptions of variables and of the study group. The second stage involved the bivariate correlation analyses between the outcome variables (caregiver burden and emotional state) and the possible predictors of these variables. The third stage aimed at verifying the model of the burden, based on theoretical and empirical assumptions (see Introduction).Verification was conducted with the help of path analysis and using the method of maximum likelihood. At the beginning, an initial model was specified, including all the potential independent variables (Fig. 1). Next, non-significant paths were deleted ($p > 0.05$). The re-

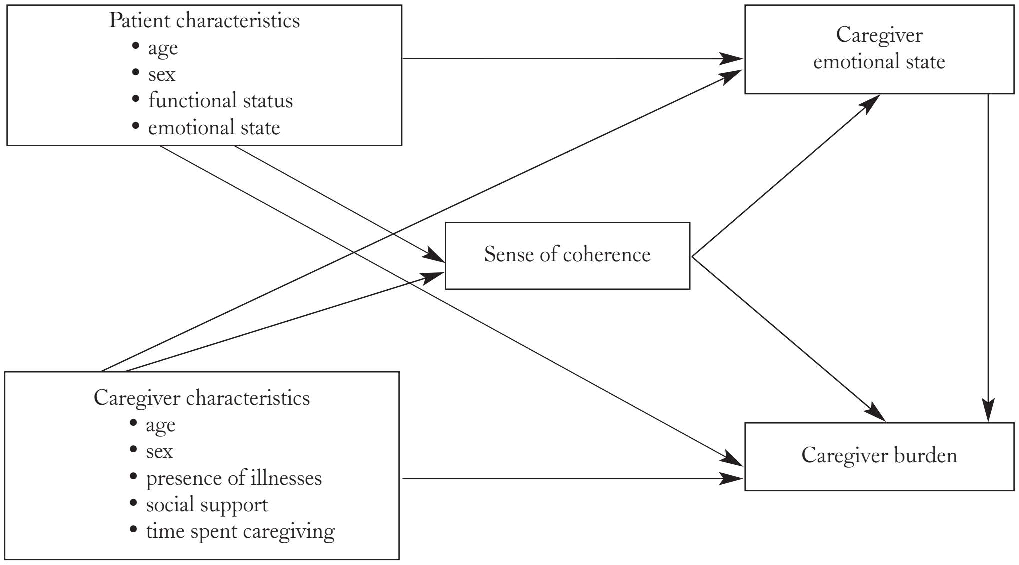

Fig. 1. Initial model of the burden in caregivers of stroke survivors

duced model underwent some minor changes, keeping the established direction of relationships between the variables. To assess the goodness-of-fit of the model, different statistical and psychometric indices were applied: the chi-square test, goodness-of-fit index (GFI), adjusted goodness-of-fit index (AGFI) and root mean square error of approximation (RMSEA). The accepted norms of these statistics are as follows: chi-square test $p > 0.05$; GFI > 0.9; AGFI > 0.9 and RMSEA < 0.05 [31]. The GFI index may be interpreted in a similar way to the determination coefficient R^2 in the multiple regression analysis. Because the chi-square test is very sensitive to deviation from the normal distribution, the Bollen and Stine bootstrap test [32] was additionally applied for goodness-of-fit assessment. Statistical analyses were conducted using the SPSS package, version 19 and AMOS, version 19.

Results

Six months following hospitalization the neurological and functional status of the patients was reasonably good, as reflected in the mean SSS and BI scores of 46.1 and 14.7 points, respectively. However, 108 (70%) of the patients still needed full help in at least one daily activity. The caregivers experienced a moderate severity of burden, which is shown in the CB Scale average score of 2.08. The average level of anxiety was elevated (mean HADS-A > 8 points). The proportion of persons with a score above the cut-off was 56%. The mean level of depressive symptoms was 5.5 points, and the percentage of subjects with scores of 8 and more was 28.7%. The HADS-T score, reflecting global psychological distress, was 14.1 (SD = 8.7). The SOC ranged within the average values (mean SOC, 141 points). The evaluation of social support was high, with the mean BSSS score 50.8. Detailed data are presented in Table 2.

Correlation analysis

Verification of the burden model was preceded by bivariate correlation analysis, in order to assess the magnitude of the relationships and to discover possible colinearity. As a result of the analyses, a significant correlation was found between the burden and seven potential predictive factors of the burden, i.e. the emotional state of the caregiver, the time spent providing care, social support and SOC, the patient's depressive symptoms and the functional and neurological status of the patient. Furthermore, a significant correlation was found between the emotional state of the caregiver and six possible predictors of this variable, i.e. SOC, social support, time spent providing care, patient's depressive symptoms, and the functional and emotional status of the patient. A co-linearity between SSS and BI ($r > 0.8$) was found and, because of this, it was decided to exclude SSS from further analyses (Table 3).

Path analysis

The initial model reflected the structure and direction of relationships between the variables, in accordance with the research hypotheses (Fig. 1). On the basis of the path analysis a final model was created, as presented in Fig. 2 and Table 4. As expected, the results showed a direct, significant association between the burden and the patient's functional status ($B = -0.36$), SOC ($B = -0.38$), the caregiver's illnesses ($B = 0.14$) and the caregiver's emotional state ($B = 0.26$). Furthermore, an indirect association was observed between the burden and the patient's functional status (mediated through SOC). No direct impact of social support on caregiver burden was found. However, its effect was manifested indirectly via SOC ($B = -0.23$). The combined set of variables explained 62% of the variance in caregiver burden.

A direct association was found between the emotional state of the caregiver and their SOC ($B = -0.65$), functional status ($B = -0.16$) and age ($B = 0.14$). An indirect influence of the patient's functional status on the caregiver's emotional state was also noted (mediated through SOC: $B = -0.16$). As with the burden, the influence of social support manifested itself only indirectly through SOC ($B = -0.28$). Altogether, the above variables explained 52% of the variance in caregiver emotional state. The fit of the overall model was acceptable with chi-square = 8.23, $df = 11$, $p = 0.69$; Bollen and Stine bootstrap test $p = 0.75$, GFI – 0.99; AGFI – 0.96 and RMSEA – 0.00.

Discussion

The aims of this study were to analyse predictive factors of caregiver's overall burden and to verify the model of the structure of an association between the burden and factors conditioning its level. The results obtained confirmed the observations by other authors that the sense of coherence, the emotional state of the caregiver and the level of the patient's disability are the key predictors of burden (see Introduction). The study also confirmed the accepted hypothesis that the level of the caregiver's emo-

Table 3. Correlation analysis between the continuous variables included in the model

	1	2	3	4	5	6	7	8	9
1. Patient's age									
2. Barthel Index	–0.28**								
3. SSS	0.13	0.81**							
4. GDS	–0.01	–0.28**	–0.20*						
5. Caregiver's age	0.21*	–0.11	–0.02	0.12					
6. Time spent caregiving	0.12	–0.52**	–0.47**	0.18*	–0.09				
7. Sense of Coherence – 29	0.10	0.25**	0.18*	–0.37**	–0.10	–0.14			
8. HADS – total score	0.002	–0.33**	–0.31**	0.33**	0.22**	0.23**	–0.69**		
9. Berlin Social Support Scale	0.01	–0.02	–0.03	–0.15	–0.17*	0.02	0.43**	–0.29**	
10. Caregiver Burden – total score	0.10	–0.55**	–0.47**	0.32**	0.17*	0.39**	–0.65**	0.57**	–0.27**

GDS – Geriatric Depression Scale, HADS – Hospital Anxiety and Depression Scale, SSS – Scandinavian Stroke Scale
$* p < 0.05$, $** p < 0.01$

tional disturbance is not only a predictor of burden, but also forms a distinct, though burden-connected, negative consequence of providing care. The latter is reflected in a different set of predictors of the burden and emotional state, different magnitudes of causal effect of the various predictors and different proportions of the explained variance in both these variables.

In the light of the results in total and direct causal effects obtained, the most important predictor of the negative consequences of caregiving was the sense of coherence. However, the influence of SOC concerned mainly the caregiver's emotional state and, to a lesser extent, the burden. In accordance with Antonovsky's concept [21], people with a strong SOC were less likely to develop depressive symptoms, anxiety and burden, than people with low levels of this dispositional orientation. Our results are similar to those obtained by other authors [18,19,22] who, using path analysis, also found a comparable direct causal effect of SOC for the severity of depressive symptoms ($\beta = -0.52$) and the level of burden ($\beta = -0.40$) in stroke patients. The above data point to the need for professional interventions aimed at bolstering this key resource which is so important for coping with stress. Interventions that could enhance particular components of SOC include interactive education of caregivers, help in understanding the situation arising, an increased sense of control over the situation, and in developing active, problem solving strategies for coping with stress [33].

As expected, another important determinant of negative consequences of caregiving was the functional state of the patient although, contrary to SOC, this variable influenced especially the burden and, to a lesser extent, the emotional state of the caregiver. The variation in the importance of the causal effect could stem from the fact that the definition of burden, as compared to emotional state, has a wider meaning and includes items of physical exhaustion that could directly reflect those caregiving activities which require physical effort. Another explanation, as reported in the literature, could be that emotional disturbances in a caregiver are caused mainly by the behavioural and emotional sequelae of stroke and, to a lesser extent, by its physical consequences [34].

In the light of the information above, it seems important to prepare families not only to provide practical caregiving activities (bathing, getting dressed, help in moving around, etc.), but also to cope with the patient's neuropsychological problems.

The poorer emotional state of the caregivers, which was reflected by their lowered mood and increased anxiety, led to the increased burden revealed in the subjects of this study.

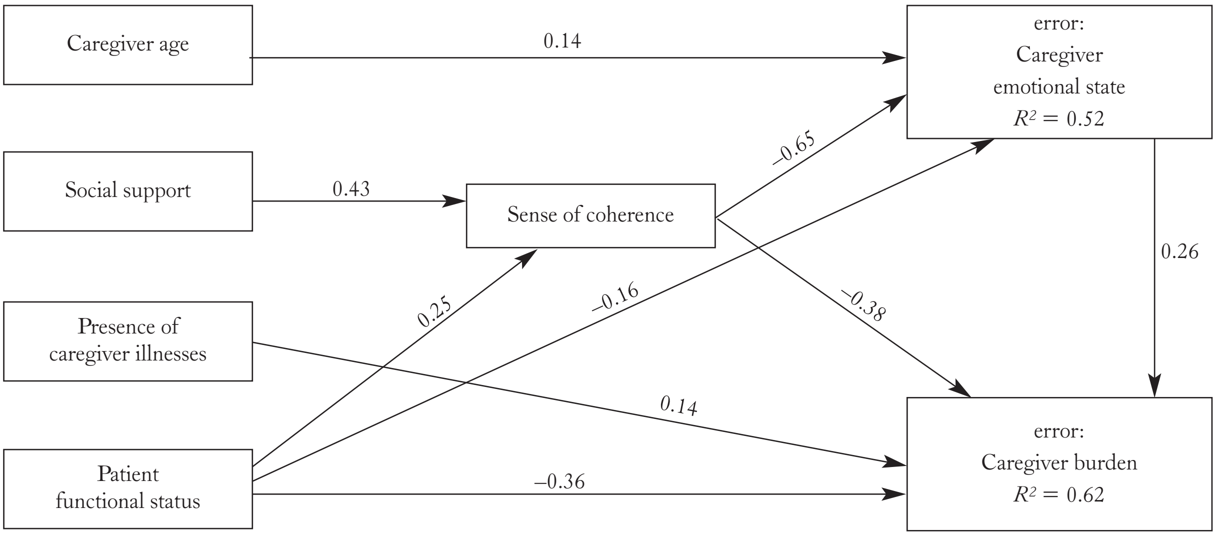

Fig. 2. Reduced model of the burden in caregivers of stroke survivors (standardized path coefficients)

These findings are in accordance with previous reports and confirm the recommendations of the other authors concerning the need for professional support programmes for informal caregivers as well as for the stroke victims [7].

Informal social support is believed by some authors to be one of the most important protective factors for the consequences of chronic stress [15]. This view was only partially supported by our study, as the influence of such social support on the burden was only minor and was revealed only by higher SOC scores. This means that while social support mobilized the caregiver's resources to cope with stress, thereby lowering the burden, it did not have a direct impact on the level of the burden or on the emotional state of the caregiver. One can therefore speculate that the social support received was not effective enough, was not free from negative interactions or was not accepted in the light of feeling a moral obligation to the patient and an attitude of exaggerated devotion by a caregiver, in the process of providing care for the patient [35-37]. A better understanding of the mechanisms of support concerning both recipients and providers needs further study.

Among other possible determinants of the negative consequences of providing care for victims are the presence of illnesses in the caregivers themselves, which may be connected with the burden, and the older age of a caregiver, which may influence their emotional state. Both factors may be important. The result showing the relevance

Table 4. Associations between variables in the model – total, direct and indirect effects (standardized coefficients)

	Caregiver age	Social support	Functional status	Caregiver illnesses	Sense of coherence	Emotional status
Total effect						
Burden	0.04	–0.23	–0.54	0.14	–0.54	0.26
Emotional status	0.14	–0.28	–0.32	0.00	–0.65	0.00
Direct effect						
Burden	0.00	0.00	–0.36	0.14	–0.38	0.26
Emotional status	0.14	0.00	–0.16	0.00	–0.65	0.00
Indirect effect						
Burden	0.04	–0.23	–0.18	0.00	–0.16	0.00
Emotional status	0.00	–0.28	–0.16	0.00	0.00	0.00

of the caregiver's health condition to the level of burden is in accordance with reports by other authors [11,16,17]. The data in previous reports referring to age form a conflicting picture since some reports showed a positive correlation between this factor and the burden, whereas others found no such correlation [13,14,18,20,22].

Conclusions

1. The burden and emotional disturbances of a caregiver are two distinct, but interconnected, consequences of providing care for a stroke patient.
2. The sense of coherence of a caregiver and the level of disability of the patient are two key predictive factors for the negative consequences of caregiving.
3. Training the families in basic nursing and personal care techniques to facilitate caring for their disabled members, and education focused on enhancing and mobilizing the caregiver's own psychosocial resources may reduce the burden and distress among caregivers of stroke patients.

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Disclosure

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