

# Caregiver's Burden of Patients 3 Years After Stroke Assessed by a Novel Caregiver Burden Scale

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**ABSTRACT.** Elmståhl S, Malmberg B, Annerstedt L. Caregiver's burden of patients 3 years after stroke assessed by a novel caregiver burden scale. *Arch Phys Med Rehabil* 1996;77:177-82.

**Objective:** To assess burden of caregivers to stroke patients three year after a primary stroke and to test validity and reliability of a novel caregiver burden scale (CB scale).

**Design:** A longitudinal community-based 3-year follow-up study of 35 consecutive primary stroke patients initially admitted to an Acute Medical Unit (mean age 82yr). The validity of the CB scale was studied in 150 patients (mean age 77yr):83 demented outpatients assessed for need of group living and 67 outpatients with stroke from a general geriatric day-care unit. Reliability was studied in another 23 outpatients (mean age 72yr) with stroke from the same unit.

**Methods:** A 22-item CB scale for different types of caregiver burden and scales for neuroticism and extroversion (Eysenck Personality Inventory) and quality of life (11-item scale). Activities of daily life were assessed by a 6-item scale, initially and 3 years later.

**Outcome Measure:** Reliability and validity of the CB scale. Improvements of activities of daily life of stroke patients.

**Results:** Factor analyses of the CB scale gave five indices—general strain, isolation, disappointment, emotional involvement, and environment—having good kappa values, .89 to 1.00 and Cronbach's alpha, .70 to .87, except for environment. A higher burden was related to a closer relationship but not to the living situation. The highest caregiver burden was found among patients showing the greatest improvements of ADL, when divided into tertiles. The patient's degree of extroversion and quality of life were negatively correlated to caregiver burden,  $-.46$  ( $p < .05$ ) and  $.59$  ( $p < .01$ ).

**Conclusions:** The CB scale proved to be a valid and reliable instrument to assess caregiver burden. To improve the caregiver situation, individual patient personality characteristics, like extroversion, feeling of quality of life, and progression of the disease, must be considered.

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**R**ESearch on family caregiving has expanded rapidly recently, and several studies have reported great burden and stress among family members caring for chronically disabled

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relatives who have stroke and dementia disorders even after institutional placement.<sup>1-3</sup> Some studies have demonstrated effects of caregiving on caregivers' emotional well-being and mental health.<sup>4,5</sup>

Theoretical models of caregiving describe the concept of burden as an outcome variable, including decreased feeling of well-being and increased health problems.<sup>6</sup> The caregiver is exposed to primary stressors that include specific care tasks and the feeling of strain or overload. Care tasks can include different activities of daily life as well as management of behavioral problems. The stressors are mediated by different coping strategies, and the specific relationship between a caregiver and a patient is important. Long-term caregiving is a dynamic process; the burden changes over time, especially for caregivers to patients with dementia disorders. Although a high proportion of patients with stroke recover and are discharged from the hospital, a majority of them report a decreased subjective quality of life several years later.<sup>7,8</sup> Increased knowledge about the patient's premorbid personality and coping strategy after stroke, as well as the caregiver's capability of support, are of great importance to the understanding of the interactions between the caregiver's feeling of burden and the patient's quality of life.

The family is still the major provider of care to the elderly in Sweden, although the society has the formal responsibility. A better understanding of the family caregiver's situation will enable intervention with specific support to reduce burden and, eventually, postpone institutionalization of the disabled. The aims of this study were to describe the situation of caregivers to stroke patients three years after the stroke event and to assess their experienced burden by a new caregiver burden scale (CB scale), and to test the reliability and aspects of validity of this modified instrument, originally developed by Oremark.<sup>9</sup>

## MATERIALS AND METHODS

### Study Population for Validation of the Caregiver Burden Scale (CB Scale)

Validity and factorial analyses were studied using family caregivers to 150 patients with dementia or stroke. Eighty-three of the patients, 9 men and 74 women, with a mean age of  $83.3 \pm 5.5$ yr had dementia according to DSM III-R criteria; 67 patients had stroke, 36 men and 31 women, with a mean age of  $69.8 \pm 19.3$ yr. Need for group living care was consecutively assessed for patients with suspected dementia according to a care program for the demented in the municipality of Malmö. Eighty-three of 100 assessed patients from 1991 to January 1993 had a family caregiver and fulfilled the criteria for dementia of Alzheimer's type or vascular dementia. Another 67 caregivers to the stroke patients were consecutively recruited during 1993 from the geriatric day-care unit at a hospital's Geriatric Department.

To study reliability (test-retest stability) of the CB scale, another 23 consecutive stroke patients, 11 men and 12 women with a mean age of  $71.8 \pm 11.5$ yr, were recruited from the geriatric day-care unit at the Geriatric Department.

### Study Population for Assessment of Caregiver Burden

The study population of caregivers and stroke patients consisted of 35 patients, 16 men and 19 women, mean age  $82.0 \pm$

7.5 yr, interviewed 3 years after their primary stroke. The city of Malmö has one hospital, and all 256 patients with a complete primary stroke who were admitted to the Acute Medical Unit during 1990 and 1991 were included in a follow-up examination 3 years later (1993 and 1994). Initially, patients underwent a clinical examination, and the diagnosis was confirmed by computed tomography (CT) scan in 83% of the cases. The patient's functional capabilities were assessed 6 days after admittance using the Katz index of activity of daily life<sup>10</sup> and a 6-item Activity index covering hygiene, ambulating, dressing, feeding, bladder function, and bowel function.<sup>11</sup> Each item scored from 0 to 6.

Ninety-eight patients were alive 3 years later and 66 fulfilled the 3-year examination. None of the 66 patients had experienced any further stroke according to history or medical examination by a physician. Eight were excluded because of dysphasia and another 22 had no primary family caregiver. The questionnaire was incomplete for 1 of the women patients; thus, 35 patients with a primary family caregiver were included in the analyses. Sixteen initially had right hemiparesis and 15 had left hemiparesis. Three years later, 8 patients had remaining right-sided and 6 patients left-sided motor impairment. Five patients were disoriented.

## Methods

The family caregiver is defined as the main responsible, informal caregiver (a relative or an otherwise related person). The recognition of the caregiver was carried out together with the psychologist and the patient. In the reliability study, this was performed by a registered nurse. The caregiver completed a questionnaire covering items on marital status, home help services; time spent weekly with the patient; type of relationship, expressed as a score from 1 to 9 (husband/wife, 1-2; son/daughter, 3-4; brother/sister, 5-6; grandchild, 7; friend/neighbor, 8; others, 9); and the CB scale. The caregiver also completed parts of the Comprehensive Psychopathological Rating Scale (CPRS) questionnaire on experience of aggressivity and depressed mood the last 3 days from the relative. The completeness of the questionnaire was checked by a psychologist or, in the reliability study, by a registered nurse.

The patient was interviewed individually by a psychologist and his or her personality and mental status were assessed using Eysenck Personality Inventory scales (EPI) on neuroticism and extroversion<sup>12</sup> and the CPRS questionnaire with items on aggressivity and depressed mood.<sup>13</sup> Life satisfaction and life quality were measured with LGC—a 10-factor scale from which one factor, "present life quality" (11 items) was chosen for the present analyses.<sup>14</sup> The awareness of the disease and the hope for improvement were assessed with a scale scored between 1 to 4 (Very Much to Not At All).

The CB scale (Caregiver's Burden Scale) was used to assess subjective burden. The scale was modified from a scale designed by Oremark<sup>9</sup> for assessment of caregivers of chronically ill persons. Four items were added to the original 20-item scale but the CB scale was then reduced to 22 items after factorial analyses including 150 caregivers (see Appendix 1). The items are all scored from 1 to 4 (Not At All, Seldom, Sometimes, Often) covering areas like the caregiver's health, feeling of psychological well-being, relations, social network, physical workload, and environmental aspects that might be important. The scale was divided into five indices—general strain, isolation, disappointment, emotional involvement, and environment—according to the factor analyses presented below. The study was approved by the local university Ethical Committee.

## Statistical Methods

A factor analysis with a principal component extraction using the varimax method for orthogonal rotation was used to examine the operationalization of the indices. Construct validity was tested by Cronbach's alpha coefficient to test the internal consistency of the five indices. A level above .70 is considered to be acceptable.<sup>15</sup> Reliability (test-retest) was tested by Cohen's kappa statistics to measure the extent of random error. The scores of all 22 items belonging to each of the 5 different indices were added for each individual and the distributions of respective sum were dichotomized as close to the median as possible. Spearman correlation coefficients, two-tailed, were used to study correlations between indices. Differences between group means were analyzed by Mann Whitney *U* Test except when otherwise stated. Kruskal-Wallis *H* test was used for trend analyses between tertiles.<sup>16</sup> A *p* > .05 was considered nonsignificant (NS).

## RESULTS

### Reliability and Validity of the CB-Scale

**Factor analyses.** The primary factor analyses included all 24 items and identified 6 indices. Two items ("Do friends or relatives appreciate your efforts" and "Does the society appreciate your efforts") negatively influenced the reliability when tested by Cronbach's alpha, and the coefficient increased from .87 to .89 when these items were excluded in a two-step fashion. After exclusion, the rotated factor analyses identified five indices—general strain, isolation, disappointment, emotional involvement, and environment—listed in Appendix 1. Results from the factor analyses are listed in table 1.

**Internal consistency.** The highest Cronbach's alpha coefficient, .87, was found for the 8-item index of general strain, while disappointment, isolation, and emotional involvement showed coefficients of .76, .70 and .70, respectively. The index for environment had the lowest coefficient, .53. The standardized item alpha was the same for all indices except for environment which had an index of .56.

**Reliability.** Twenty-three caregivers took part in a reexamination 2 weeks after the first examination. The kappa values

Table 1: Factor Analysis of the 22 Items in the Indices of Caregiver's Burden

Item	Factors				
	1	2	3	4	5
General strain	1	.61			
	2	.74			
	3	.57			
	4	.71			
	5	.74			
	6	.64			
	7	.54			
	8	.66			
Isolation	9		.82		
	10		.63		
	11		.53		
Disappointment	12			.77	
	13			.78	
	14			.62	
	15			.49	
	16			.51	
Emotional involvement	17				.80
	18				.68
	19				.72
Environment	20				.85
	21				.48
	22				.71

Factor coefficients larger than .47 are presented (*n* = 150). Items are listed in the Appendix.

Table 2: Reliability of the Different Caregiving Indices by Marital Status and Gender of the Caregiver and Patient

	Marital Status		Gender of Caregiver		Gender of Patient		Total
	Married	Others	Male	Female	Male	Female	
Subjects (no.)	15	8	12	11	11	12	23
Burden	.82 ± .33	1.00 ± .00	1.00 ± .00	.73 ± .48	.77 ± .41	1.00 ± .00	.89 ± .21
General strain	.86 ± .25	1.00 ± .00	1.00 ± .00	.79 ± .38	.81 ± 1.00	1.00 ± .00	.90 ± .18
Isolation	1.00 ± .00	1.00 ± .00	1.00 ± .00	1.00 ± .00	1.00 ± .00	1.00 ± .00	1.00 ± .00
Disappointment	.87 ± .24	1.00 ± .00	.82 ± .33	1.00 ± .00	1.00 ± .00	.83 ± .31	.91 ± .17
Emotional involvement	1.00 ± .00	.67 ± .56	.78 ± .39	1.00 ± .00	.75 ± .44	1.00 ± .00	.90 ± .21
Environment	.71 ± .37	.57 ± .67	.74 ± .46	.53 ± .51	.55 ± .55	.79 ± .37	.69 ± .32

Reliability given as kappa values ± 95% confidence limits ( $n = 23$ ).

varied from .53 to 1.00 and all indices except environment had kappa values between .89 to 1.00 (table 2). There was no consistent pattern for gender or marital status.

**Correlation analyses.** The internal correlation between the different indices are listed in table 3. The index of general strain showed the highest correlation to other indices of burden with coefficients between .38 to .55. Correlation analyses were also performed between the indices and the number of years of caregiving and type of relationship. A tendency toward a negative association was found between, on the one hand, disappointment and isolation ( $r = -.13$ ,  $p = .05$ , and  $r = -.11$ ,  $p = .09$ ), and, on the other hand, years of caregiving. A closer relationship was correlated to a higher degree of general strain ( $-.14$ ,  $p < .05$ ), isolation ( $-.23$ ,  $p < .01$ ), disappointment ( $-.27$ ,  $p < .0001$ ), and emotional involvement ( $-.21$ ,  $p < .01$ ). The corresponding correlation coefficient between the type of relationship and total burden including all 22 items was  $-.23$ ,  $p < .01$ .

### Stroke Patients and Burden for Caregivers

The caregiving situation was studied in 35 patients 3 years after a primary stroke. The type of relationship and gender are listed in table 4. Twenty-nine of the caregivers had full-time or part-time work. The mean weekly time of assistance was less than 10 hours for half of the caregivers. Spouses who were caregivers spent more time than other caregivers and their relatives had less home help services (table 5). Spouses experienced the same total burden as children and other caregivers but a higher degree of disappointment and isolation. The stroke patient's degree of aggressivity, depressed mood, neuroticism, and extroversion did not differ between these groups. There was no significant difference of any kind of burden if the stroke patients lived alone ( $n = 18$ ) or together with the caregiver or at homes for the elderly.

Stroke patients' ability to cope with activities of daily life was measured with an Activity Index (AI) and Katz ADL index. The initial mean AI was  $22.9 \pm 8.4$  compared with  $31.5 \pm 7.4$  3 years after the stroke. Seventeen patients were independent according to the Katz index (score A), another 6 were dependent on one activity (B), and 12 patients were dependent on two or more activities at reexamination. Caregivers' burdens were the same between these Katz index groups (A vs others; A+B vs others), but when patients were divided into tertiles according

to the changes of AI between the initial assessment 1 week after the stroke and the assessment 3 years later, caregivers to patients with the greatest improvements, thus belonging to the highest tertile, experienced higher total burden ( $2.1 \pm .59$  vs  $1.7 \pm .47$ ;  $p = .05$ ) and emotional involvement ( $2.1 \pm .93$  vs  $1.5 \pm .49$ ;  $p = .02$ ) than the others (table 6). No significant differences in assessed quality of life were noted between patients with different ADL competence at past or present measurements. Data on ADL competence at past or present measurements. Data on ADL competence were analyzed separately and also categorized into independent or independent ADL competence.

Two dimensions of personality, extroversion and neuroticism, were measured, and the EPI scores are listed in table 7. No differences were found between gender and age groups among the stroke patients. The caregivers described a higher degree of aggressivity and depressed mood among the patients than the findings from the observation and interview by the psychologist ( $1.3 \pm .54$  vs  $0.1 \pm .34$ , and  $1.3 \pm .46$  vs  $0.7 \pm .44$ , respectively,  $p < .0001$ ). Caregivers to patients with an extrovert personality showed less burden, general strain, and influence of environment. There were stronger correlations between the occurrence of depressed mood assessed by the caregiver and caregiver burden than the independent observation of mood by the psychologist (table 8). Analyses of the factor measuring quality of life showed that decreasing experience of good quality of life among patients was negatively correlated to caregivers "burdens" for all indices except isolation and emotional involvement. The coefficients were in the order of .37 to .59.

### DISCUSSION

The method to assess caregiver's burden, the CB scale, shows excellent reliability with kappa values .69 or higher for all indices. The internal consistency, as measured by Cronbach's alpha coefficient, showed values above .70 considered as acceptable for all indices but environment.<sup>15</sup> The different indices were intercorrelated but the low coefficients indicate that the separate indices add specific information about different aspects of subjective burden. Using the varimax method for the orthogonal rotation in the factor analyses should minimize the number of variables with high factor loadings in the specific factor. Therefore, an item with low loading, like item 15 ("Do you find it physically trying...") describing an unspecific feeling similar to general strain, shows the best goodness of fit in the

Table 3: Spearman Correlation Coefficients Between the Different Indices of Caregiver's Burden

	General Strain	Disappointment	Emotional Involvement	Isolation	Environment
Disappointment	.55*	1.00	.27*	.56*	.39*
Emotional involvement	.45*	.27*	1.00	.27*	.09
Isolation	.59*	.56*	.27*	1.00	.33*
Environment	.38*	.39*	.09	.33*	1.00

\*  $p < .001$  ( $n = 150$ ).

Table 4: Family Caregiver's Gender and Type of Relationship to Stroke Patients ( $n = 35$ )

	Spouses	Children	Siblings/Others
Male caregivers	7	3	0
Female caregivers	12	10	3
Total	19	13	3

**Table 5: Mean Values of Experienced Burden for Different Types of Caregivers Taking Care of Stroke Patients**

	Spouses (n = 19)	p	Children and Others (n = 16)
Home help services (hrs/wk)	3.4 ± 3.6		7.0 ± 10.7
Assistance from caregiver,* mean hours weekly			
Less than 10 hours	14%	<.001	86%
10 to 20 hours	7%		14%
More than 20 hours	79%		0%
Total burden	2.0 ± 0.5	NS	1.7 ± 0.5
General strain	2.2 ± 0.8	NS	1.9 ± 0.8
Disappointment	2.1 ± 0.8	<.05	1.6 ± 0.5
Isolation	2.1 ± 0.6	<.01	1.4 ± 0.5
Environment	1.7 ± 0.7	NS	1.7 ± 0.5
Emotional involvement	1.7 ± 0.6	NS	1.6 ± 0.8

\*  $\chi^2$  test used for analysis.

disappointment factor. The names of the factors have been assigned according to the factor with the highest loading and should be regarded as tentative. For example, the factor disappointment includes item 14, "Do you feel lonely and isolated..." with a lower factor loading than item 12 concerning feelings about unfair treatment. Furthermore, items should not be interpreted separately.

Research on the informal care of the disabled elderly has been recognized in recent decades. Formal care refers to home help services and other types of care provided by the public society, whereas informal care is provided by relatives. Previous study by Malonebeach and Zarit<sup>17</sup> has focused on methodological aspects like definitions of caregiver, selection bias, and the quality of the relation between the caregiver and relative. In a recent Swedish study, Johansson and Thorslund<sup>18</sup> showed that in a nationwide sample of noninstitutionalized elderly, 10% of those aged 75 to 84 years needed help with some type of basic ADL and almost a third needed help with instrumental ADL like laundry and cleaning. Informal care given by husband, wife, children, or relatives were two to three times greater than formal care from the public service. There was also a strong preference among elderly for informal support. We found no differences in total burden if the patient lived alone or with the caregiver. Whether this is explained by different types of burden between the caregiver groups or lack of power to detect minor differences needs to be analyzed in further studies.

In this study the caregiver was defined as a person, in most

**Table 6: Burden of Caregivers in Relation to Changes in Stroke Patients' Abilities to Perform Activities of Daily Life After 3-year Follow-Up**

	Difference of Activity Index 3 Years After Stroke			p for Trend ( $\chi^2$ test)
	I (Lowest)	II	III (Highest)	
No.	10	13	11	
Activity index (median) difference, years 3-0	-1.5	7	17	—
Total burden	1.59 ± .44	1.81 ± .50	2.13 ± .59	.11
General strain	1.78 ± .73	1.99 ± .76	2.35 ± .83	.29
Disappointment	1.58 ± .68	1.86 ± .64	2.27 ± .72	.07
Isolation	1.67 ± .62	1.72 ± .62	2.07 ± .81	.52
Environment	1.33 ± .29	1.78 ± .70	1.96 ± .70	.10
Emotional involvement	1.37 ± .46	1.62 ± .51	2.09 ± .93	.13
Activity index year 3	26.6 ± 10.6	34.2 ± 3.0	32.4 ± 5.1	.16
Katz ADL index year 3				
A	50%	61%	36%	
B	0%	15%	36%	
C-G, Ö	50%	24%	28%	

Data given as tertiles.

**Table 7: Psychological Characteristics of Stroke Patients**

	Age		Gender	
	≤75	>75	Male	Female
No.	21	12	16	17
Extroversion	12.4 ± 3.3	14.4 ± 3.7	12.7 ± 2.9	12.7 ± 3.7
Neuroticism	7.4 ± 4.0	6.0 ± 2.7	6.0 ± 4.1	7.7 ± 3.6
Aggressivity (0 to 3.0) according to caregiver	1.4 ± 0.6	1.3 ± 0.5	2.8 ± 1.0	2.6 ± 1.2
Aggressivity according to observer	0.1 ± 0.3	0.1 ± 0.4	0.1 ± 0.2	0.2 ± 0.4
Depressed mood (0 to 3.0) according to caregiver	1.3 ± 0.5	1.3 ± 0.5	1.2 ± 0.4	1.4 ± 0.5
Depressed mood according to observer	0.7 ± 0.5	0.6 ± 0.2	0.7 ± 0.2	0.7 ± 0.5
Quality of life	3.6 ± 2.3	4.7 ± 2.0	3.4 ± 2.2	4.4 ± 2.3

cases a close relative, ie, spouse or child, who was the main provider of help due to impaired functional ability and health, according to the patient. To avoid selection bias, caregivers and patients who were unable to participate at the hospital were interviewed at home. The great differences in formal care received by patients indicate some heterogeneity of the study population. No significant correlations were found between caregivers' burdens and formal care, expressed as weekly hours of home help services (Spearman correlation coefficient .22, NS). It seems that types of formal support to caregivers other than home help service are needed to decrease experienced burden and that the support should be individualized.

The caregiving of relatives with stroke and dementia have some similarities. Both diseases are disabling conditions with physical and often cognitive impairment with behavioral problems that might be difficult to cope with. Dementia comprises different types, and the most important forms are Alzheimer's dementia, vascular dementia, and combined forms. The situation of caregivers to elderly with Alzheimer's dementia differs in one important aspect. Alzheimer's dementia has a continuously deteriorating course, whereas stroke and vascular dementia might have periods of stable conditions. The types of burden and stress could differ depending on the type of the patient's disease. In a population-based study of 474 demented and non-demented elderly, the caregivers reported limitations of their affective and social life compared with relatives of non-demented subjects.<sup>5</sup> This type of burden was similar to the findings in this study. We have also studied caregivers to demented elderly in a previous study, and the spouses reported similar burden, general strain, and isolation (personal communication, 1995).

The outcome of the stroke patients between the initial examination and the 3-year follow-up indicates a good recovery. None of the patients were independent in ADL at the beginning, compared with 50% 3 years later, and a further 18% of the patients were dependent on only one factor at the last examination. This is similar to reported data from a 4-year follow-up of Finnish stroke patients, 87% of whom were independent in ADL.<sup>7</sup> In that study, the mean age was only 48 years. In a previous Swedish study, 67% of stroke patients were ADL-independent 1 year after stroke.<sup>14</sup> In that study, the ADL competence showed the strongest correlation with assessed quality of life and the analyses included a variety of variables like diagnosis, coping, and personality using the same questionnaire as in this study. We could not find any significant correlations between present or past ADL competence and experienced quality of life of the

**Table 8: Spearman Correlation Coefficients Between Experienced Burden Among Caregivers in Relation to Psychological Characteristics of the Stroke Patients**

Patient	Caregiver					
	Total Burden	General Strain	Disappointment	Isolation	Environment	Emotional Involvement
Extroversion	-.46*	-.47*	.26	-.38	-.40*	-.26
Neuroticism	.21	.10	.37	.13	.07	.36
Aggressivity						
According to caregiver	.24	.22	.20	.09	-.09	.71 <sup>†</sup>
According to observer	.12	.11	.27	.25	-.07	.49 <sup>†</sup>
Depressed mood						
According to caregiver	.36*	.38*	.35*	.15	.37*	.10
According to observer	.22	.25	.13	.07	.39*	.16
Quality of life	.59 <sup>†</sup>	-.44*	-.44*	.37	.48*	-.38

\*  $p < .05$ .†  $p < .01$ .‡  $p < .001$ .

stroke patients. In a previous study, Viitanen and colleagues<sup>19</sup> reported a decrease of life satisfaction related to motor impairment in stroke patients after a 4- to 6-year follow-up. About 40% of the stroke patients had motor impairment, which was similar to our findings. However, in that study the global assessment of quality of life also included an item on self-care ADL, which might explain the correlation between ADL competence and global quality of life. The level of quality of life after stroke is dependent on several factors like the person's premorbid personality, marital status, coping, and capability to reorientate. ADL ability has only a marginal effect on social well-being or quality of life, which is a finding supported by previous studies.<sup>7,19,20</sup>

Surprisingly, caregivers to patients showing the greatest improvements in ADL functions also reported the highest total burden and disappointment. Whether this should be interpreted as a lack of awareness of actual abilities among the stroke patients is unclear. The interview by the psychologist showed no correlations between patients' assessed awareness of the disease, capabilities, and hope for improvement, and degree of burden (correlation coefficients ranged between  $-.30$  to  $.16$ , NS). However, the caregiver might also provide some secondary emotional benefits from other family members or relatives, and the patient's improvement will then be a threat and cause increased burden. As expected, we found a negative consistent correlation between the caregiver's burden and quality of life for stroke patients. This finding seems important to verify in further studies to identify possible predictors of high burden that might eventually lead to the breaking point, when the caregiver is unable to take care of the relative. A better understanding of this mechanism could improve the public services, offering better social support to caregivers as well as stroke patients. The type of support can be some kind of relief from caring, using day care units or short periods of care in institutions. Other types of individual psychological and social support might be needed.

In conclusion, the CB scale showed good construct validity and test-retest stability according to statistical analyses, and different types of burden among caregivers could be distinguished. The 3-year follow-up study of stroke patients and their caregivers showed that the degree of burden depends on several aspects, like the patient's personality characteristics, the caregiver's social characteristics, and the progression of the disease. The public service could give further support to caregivers by taking these aspects into consideration and thereby postponing institutionalization.

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## APPENDIX

### The Five Factors of the CB Scale

#### *General strain.*

1. Do you find yourself facing purely practical problems in the care of your relative that you think are difficult to solve?
2. Do you think you have to shoulder too much responsibility for your relative's welfare?
3. Do you sometimes feel as if you would like to run away from the entire situation you find yourself in?
4. Do you feel tired and worn out?
5. Do you feel tied down by your relative's problem?
6. Do you find it mentally trying to take care of your relative?
7. Do you think your own health has suffered because you have been taking care of your relative?
8. Do you think you spend so much time with your relative that the time for yourself is insufficient?

#### *Isolation.*

9. Do you avoid inviting friends and acquaintances home because of your relative's problem?

10. Has your social life, eg with family and friends, been lessened?
11. Has your relative's problem prevented you from doing what you had planned to do in this phase of your life?

#### *Disappointment.*

12. Have you a feeling that life has treated you unfairly?
13. Had you expected that life would be different than it is at your age?
14. Do you feel lonely and isolated because of your relative's problem?
15. Do you find it physically trying to take care of your relative?
16. Have you experienced economic sacrifice because you have been taking care of your relative?

#### *Emotional involvement.*

17. Are you sometimes ashamed of your relative's behaviour?
18. Do you ever feel offended and angry with your relative?
19. Do you feel embarrassed by your relative's behaviour?

#### *Environment.*

20. Does the physical environment make it troublesome for you taking care of your relative?
21. Do you worry about not taking care of your relative in the proper way?
22. Is there anything in the neighbourhood of your relative's home making it troublesome for you to take care of your relative?