Caregiver burden after stroke: a 10-year follow-up study of Polish caregivers for stroke patients

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Abstract

Background A long-term assessment of stroke outcomes from the perspectives of patients and their caregivers is important for optimising long-term post-stroke care. The extended effects of stroke caregiving, particularly caregiver burden beyond 5 years since stroke, remain to be determined. Hence, this study aimed to determine caregiver burden at 10 years after stroke, compare the burden severity at 10 years with its levels at 5 years and 6 months after stroke, and identify predictors of the burden severity at 10 years post-stroke.

Methods A longitudinal follow-up study including a group of first-ever stroke patients/informal continuous caregivers pairs was followed for 10 years and interviewed face-to face at their home setting.

Caregiver burden was evaluated with the Caregiver Burden Scale. Potential predictors were examined using standardised measures and identified by applying the Classification and Regression Tree.

Results A total of 40 caregiver/patient pairs participated in the study. At 10 years, 47.5% of the caregivers experienced a considerable burden. This was more than after 5 years (17.5%) and comparable to that after 6 months (37.5%), $p < 0.003$. Longer time spent caregiving, caregivers' weaker sense of coherence, more severe stroke, and caregivers' anxiety were the independent predictors of considerable burden 10 years after stroke.

Conclusions Caregivers' burden in the late chronic post-stroke phase is a significant problem, as nearly half of the caregivers experience a substantial burden. This problem mainly concerns individuals who spend at least 7 h daily caregiving and have a lower Sense of Coherence.

The long-term evaluation of stroke consequences reported by stroke patients and their caregivers can be an important source of information for healthcare professionals in order to optimise the care and support they provide at various stages of life after stroke.

Keywords Caregiver, Burden, Survivor, Stroke

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Introduction

Stroke is a disease characterised by a sudden onset and can have serious short and long-term consequences for both individual patients and societies [1]. It ranks as a leading cause of disability-adjusted life years lost worldwide [2]. Over the past 20 years, there has been significant progress in stroke management increasing the chance of survival and recovery during the acute and early post-stroke phases [3, 4]. However, the longer-term effects remain a significant concern [5]. Research showed that 5 to 6 years after stroke, approximately 50% of patients die, 25% have a recurrent stroke, and about 20 to 45% are functionally dependent [6–11]. At ten years, these figures are as follows: 70%, 40—50%, and 29—50%, respectively [7, 11–13].

The consequences of stroke affect not only patients but also their loved ones, usually family members, who take over the care responsibilities after the hospital discharge [14]. Family caregivers, and more broadly, informal caregivers, play a crucial role in poststroke recovery, providing patients with practical, emotional and spiritual support [15]. They begin to fulfil their caregiving role immediately upon the patient's return from the hospital and continue it for several months or years, going through various stages, during which they might encounter significant difficulties and challenges, specific to each stage [16].

Regardless of the time elapsed since the stroke and the duration of caregiving, if the challenges are big and the caregivers' resources are limited along with insufficient external support, a substantial burden arises [17, 18]. This is broadly defined as "the extent to which caregivers perceived their emotional, physical health, social life, and financial status as a result of caring for their relative" [19] (p. 261).

Many studies investigated the burden among stroke caregivers during the last two decades, but only a dozen of them examined it longitudinally [16, 20–22]. These studies showed that 22.7% to 59% of caregivers experienced an elevated burden during the first 6 months after hospital admission, hospital discharge, or admission to rehabilitation [20–22], 20.8% to 52% after 1 year [20, 21], 43% at 3 years, and 30% at 5 years [21, 23] which indicates that caregivers gradually adapt to changes caused by their loved one's illness.

However, what happens in a more distant period, when caregivers age, some patients experience a recurrent stroke or late stroke-related and health-related changes and their functional status deteriorates? [13, 24, 25]. The literature does not answer this question as, to the authors' best knowledge, there are no longitudinal studies beyond the 5 years. Hence, they decided to continue their previously conducted research [23, 26] to determine and further understand the long-term consequences of stroke in terms of burden, its evolution, and determinants. By doing this, the study fits into one of the key targets specified in the Action Plan for Stroke in Europe 2018–2030 [27], pointing to the need for research based on patient and carer reports on life after stroke covering the entire lifespan in order to optimise a lifelong care following stroke.

The aims of this study therefore were: 1) to describe the caregiver burden at 10 years after stroke, 2) to compare the burden severity at 10 years with its levels at 5 years and 6 months after the event, and 3) to identify patient and caregiver characteristics determining the burden severity at 10 years post-stroke.

Participants and methods

Design

A longitudinal prospective follow-up design was adopted in the study. The study was conducted in the city of Poznań and its surrounding areas, within approximately 100 km from Poznań, in the Great Poland Voivodeship (a voivodeship being the highest-level administrative division of Poland). Poznań is located in the central-western part of Poland, in the central area of the voivodeship and has a population of over 500.000.

Participants

A group of caregivers of stroke patients consecutively hospitalised in the stroke subunit of the neurological department at the Voivodeship Hospital (formerly the Voivodeship Integrated Hospital) in Poznań due to their first-ever stroke between 2005 and 2008 were enrolled. The patients were assessed at discharge, and subsequently, the patient/caregiver pairs were examined 6 months later (Time 1, T1), then 5 years after T1 (Time 2, T2), and again after an additional 5 years (Time 3, T3), resulting in a total observation period of over 10 years. Results of the T1 and T2 assessments have been published earlier [23, 26].

The current assessment focuses on the 10-year outcome of continuous caregiving and possible changes in the burden severity seen from a more distant perspective. Details about the sampling, the initial sample, and data collection procedures were presented elsewhere [23, 26]. In brief, the inclusion criteria for the patients comprised a first-ever stroke diagnosis, functional deficits at discharge, no other disabling or psychiatric conditions, pre-stroke independence in activities of daily living, and returning home after discharge. For the caregivers, they were as follows: being the primary caregiver, not receiving payment for caregiving, and not simultaneously providing long-term care for another individual at home.

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Initially, during the patient's hospitalisation, 223 patient/caregiver pairs were enrolled in the study. Between discharge and T1, 73 pairs were withdrawn due to patient deaths ($n=34$), relocation to a care facility ($n=4$), staying in a rehabilitation or other hospital ($n=5$), inability to locate or failure to contact ($n=14$), and refusal to participate ($n=16$). Consequently, at T1, a group of 150 pairs took part in the study, and 88 at T2 (62 pairs were withdrawn since T1). Altogether, between T1 and T3, 110 participants dropped out, the reason being: a patient's death ($n=35$), transfer to a care facility ($n=2$), a caregiver's death ($n=1$), discontinuation of caregiving ($n=6$), refusal to participate ($n=4$), and an inability to locate ($n=62$). As a result, the final group consisted of 40 stroke patients and 40 caregivers. Before the T3 investigation, as before the previous ones, the participants were contacted personally by telephone, post, or mail. Those reached were asked whether they would be willing to participate in the follow-up study, and in case of agreement, the caregiver/patient pair was visited and interviewed in their homes by the same researchers as in T1 and T2.

Research measures

The same measures were used as in T1 and T2 [23, 26]; therefore, they are only characterised in brief.

Caregiver measures

The 22-item Caregiver Burden Scale (CBS) [28, 29] was used to assess the burden. The scale consists of 5 subscales, each scored from 1 to 4, with the total score ranging from 1 to 4, where a score of 2 or more denotes considerable burden. The total scale and subscale scores are counted as the mean values of the items included in the respective subscales and the entire scale. The 14-item Hospital Anxiety and Depression Scale (HADS, scored 0—21) [30] was applied to measure anxiety (HADS – A) and depression (HADS – D). The 8-item Berlin Perceived Social Support Scale (PSSS, scored 8 – 32) [31] was employed to measure social support. The 13-item Antonovsky Sense of Coherence Scale (SOC, scored 13—91) [32] was utilised to assess the caregivers' inner resources for dealing with stressful life events. A single item (scored 1–5) from the WHOQoL-Bref [33] was used to evaluate overall satisfaction with health.

Patient measures

The Scandinavian Stroke Scale (SSS, scored 0—58) [34] and the Barthel ADL Index (BI, scored 0–20) [35] were applied to assess stroke severity and functional limitations.

The participants' sociodemographic data and the patients' clinical information were gathered from the medical records and with the help of a semi-structured questionnaire.

Statistical analysis

Descriptive statistics of the continuous variables were displayed as means, ± standard deviations (SD), min.-max., ranges, and categorical data were presented as numbers and percentages. Changes in the CBS scores and caregiver/patient characteristics between T1 and T3 were examined using the Cochrane *Q* test [36] and Friedman test [37] in conjunction with the Dunn and Conover-Iman post-hoc tests, respectively when the omnibus tests showed significant results. Supplementary to these analyses, a latent class analysis (LCA) [38] using observed polynomial measurement items was employed to identify a categorical latent variable, i.e. possible patterns of the caregiver burden change between T1 and T3 represented by mutually exclusive and internally homogeneous latent classes with the most likely members assigned to each class [38].

Associations between the caregiver burden and caregiver/patient characteristics at T3 were examined by the chi-square test, the exact Fisher test, the Student t-test, and the Mann–Whitney U test, depending on the type of variables and their distribution [39]. Possible predictors of burden severity at T3 were identified using the Classification and Regression Tree (CART) data mining method [40]. Based on multiple recursive algorithms, this method enables the prediction of a dependent variable (here, CBS: considerable and low) by determining the influence of independent variables. The significance level was established at $p \leq 0.05$, and all tests were two-tailed. Data were analysed with the Statistica 13 Package (TIBSCO Software Inc. 2017) and the R Package lcmm [41].

Ethical considerations

The study was approved by the Bioethics Committee at the University of Medical Sciences in Poznań (no.1365/05; 32/10; 283/12). All candidates for the study were informed about the study, and those who agreed to participate gave their informed written consent. The study was carried out in accordance with the principles of the Helsinki Declaration.

Results

Characteristics of participants

As mentioned above, a total of 40 caregiver/patient pairs participated in all three follow-up assessments. The caregiver group consisted of 32 (80%) women and 8 (20%) men, with a mean age of 62.75 (SD=11.24; range 39 – 83), mostly aged 60 or older ($n=28$, 70%), the patients' spouses ($n=28$, 70%), living in the same house ($n=38$, 95%). Most were retired or on disability

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pension ($n=27$, 67.5%), 7 (17.5%) were professionally active, and the remaining had other sources of income. The patient group comprised 17 (42.5%) women and 23 (57.5%) men with a mean age of 66.90 (SD $=10.71$ years; range 39—91), also in the majority over 60 years old ($n=33$, 82.5%). According to the inclusion criteria, all the patients demonstrated a functional deficit at discharge (mean BI $=4.7$; SD $=4.5$). Nine patients (22.5%) had recurrent strokes between T1 and T2.

There were no significant differences between the T3 participants and those who dropped out between T1 and T3 regarding the caregiver's gender ($p=0.603$), age ($p=0.688$), caregiver/patient spousal relationships ($p=0.073$), living arrangement at T1 ($p=0.631$) and patients' SSS ($p=0.781$) and BI ($p=0.748$) at discharge and T1. The only difference was the patients' age; those who dropped out were significantly older (66.45 years, SD $=12.45$ vs 57.18 years, SD $=10.66$; $U=1249$, $p<0.001$).

Caregiver burden, caregiver/patient characteristics at T3 and their changes between T1 and T3

At T3, the proportion of the caregivers experiencing considerable burden was significantly greater than at T2 (the post-hoc Dunn test with Bonferroni adjusted $p=0.006$) and comparable to that at T1. The average scores for the CBS total and its two subscales (General strain and Disappointment) followed a similar pattern. Also, the

mean time spent caring per day at T3 was longer than at T2 and comparable to that at T1. The rest of caregiver/patient characteristics did not change significantly over time (Table 1). However, with respect to functional status, a detailed analysis of individual BI items at T2 and T3 revealed that at T3, the number of patients requiring assistance increased in 7 out of 10 activities. For instance, there was an increase in dressing by 7 individuals, in stairs use and bathing—by 6 individuals in each, and in toilet use and feeding—by 5.

In addition to the above results, Fig. 1 shows possible patterns of the burden severity over time according to the CBS total score revealed by the LCA. As can be seen, three trajectories (classes) were identified: 1) high, low and high (red line, $n=5$, 12.5%), 2) constantly low (CBS <2; green line, $n=17$, 42.5%), and 3) constantly high (CBS ≥ 2, blue line, $n=18$, 45%). There were no significant differences in terms of caregivers' self-rated health, HADS-A score, SOC, social support as well as caregivers' and patients' gender, age, and caregiver-patient relationships.

However, there were significant differences between these three classes regarding time spent caregiving: Class 1: mean (SD) $=10.0$ h (9.6) vs Class 2: 2.1 (2.6) vs Class 3: 8.9 (7.7); HADS-D: Class 1: mean (SD) $=7.2$ (2.9) vs Class 2: 4.4 (2.4) vs Class 3: 7.6 (3,9); SSS score: Class 1: mean (SD) $=48.2$ (4.1) vs Class 2: 53.3 (5.0) vs

Table 1 Caregiver/patient characteristics and caregiver burden over time (in bold, *p*-values ≤ 0.05)

	Time 1	Time 2	Time 3	test statistic	*p* value
Caregiver burden					
General strain, mean (SD)	2.18 (0.75)[a]	1.92 (0.90)[b]	2.22 (0.97)[a]	$\chi^2=8.43$	**0.015**
Isolation, mean (SD)	1.88 (0.90)[a]	1.57 (0.89)[b]	1.66 (0.94) [b]	$\chi^2=11.58$	**0.003**
Disappointment, mean (SD)	2.25 (0.74)[a]	1.98 (0.84)[b]	2.40 (0.98)[a]	$\chi^2=10.50$	**0.005**
Emotional involvement, mean (SD)	1.56 (0.77)	1.45 (0.77)	1.52 (0.87)	$\chi^2=2.89$	0.236
Environment, mean (SD)	1.72 (0.44)[a]	1.17 (0.44)[b]	1.08 (0.28)[b]	$\chi^2=48.85$	**<0.001**
Total score, mean (SD)	2.01 (0.63)[a]	1.62 (0.65)[b]	1.93 (0.75)[a]	$\chi^2=24.09$	**<0.001**
Considerable burden, n (%)	15 (37.5)	7 (17.5)	19 (47.5)	$\chi^2=11.79$	**<0.003**
Caregiver variables					
HADS-A, mean (SD)	8.55 (4.01)	7.03 (4.63)	7.43 (4.55)	$\chi^2=3.50$	0.174
HADS – D, mean (SD)	5.37 (4.61)	5.40 (4.33)	6.15 (3.51)	$\chi^2=2.35$	0.309
PSSS, mean (SD)	28.13 (5.77)	28.35 (5.74)	27.45 (6.32)	$\chi^2=1.43$	0.490
SOC, mean (SD)	66.8 (12.40) [a]	63.58 (15.07) [a]	60 (12.08) [b]	$\chi^2=21.58$	**<0.001**
Self-rated health, unsatisfied, n (%)	22 (55)	17 (42.5)	16 (40)	$Q=3.65$	0.161
Time spent caring/day, mean (SD)	6.67 (5.10) [a]	5.43 (6.40) [b]	6.12 (7.13) [a]	$\chi^2=13.41$	**0.001**
Patient variables					
SSS, mean (SD)	46.85 (9.70)	48.02 (9.94)	47.05 (5.40)	$\chi^2=3.49$	0.175
BI, mean (SD)	15.73 (4.80)	16.40 (4.56)	15.48 (5.40)	$\chi^2=5.10$	0.078

Means that have no *superscript* in common are significantly different from each other at *p* ≤ 0.05

Abbreviations: HADS Hospital Depression and Anxiety Scale, *PSSS* Perceived Social Support Scale, *SOC* Sence of Coherence Scale, *SSS* Scandinavian Stroke Scale, *BI* Barthel Index, *SD* Standard deviation, *n* number

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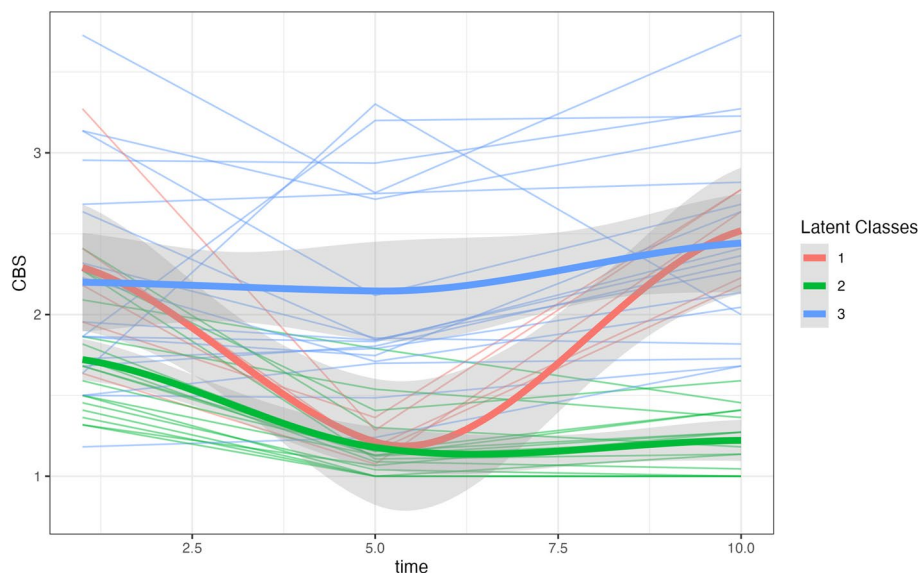
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Fig. 1 Trajectories of the caregiver burden level as a function of time. Legend: The thick coloured lines with grey shading show the extrapolated profiles of caregiver burden over time by distinguished class. The thin lines represent the actual profiles of individual subjects. Abbreviations: CBS, Caregiver Burden Scale

Class 3: 40.8 (10,9); and BI: Class 1: mean (SD) = 14.8 (3.8) vs Class 2: 18.6 (2.0) vs Class 3: 12.7 (6.4).

The Classes 1 and 3 were characterised by a significantly ($p < 0.05$) longer time spent caring per day, more pronounced caregiver depressive symptoms (HADS-D), stroke symptoms (SSS) and functional deficit (BI) among the patients than the Class 2.

This 3-class model fitted the data best when compared to the 1 and 2-class models: AIC = 253.62 (1 Class) vs 169.15 (2 Classes) and 156.04 (3 Classes); BIC = 256.99 (1 Class) vs 191.10 (2 Classes) and 184.76 and (3 Classes).

Associations and predictors of considerable burden at 10 years after stroke

Among the caregiver/patient characteristics, six were significantly related to the burden severity at T3 in bivariate analysis (Table 2).

Four of them were identified as predictors of the considerable burden in the CART analysis: longer time spent caregiving (≥ 7 h: considerable burden, $n = 11$ vs low, $n = 1$; node 3), lower SOC (≤ 53: considerable burden, $n = 5$ vs low, $n = 1$; node 4), more severe stroke impairment (SSS ≤ 42: considerable burden, $n = 2$ vs low, $n = 0$, node 6) and anxiety symptoms (HADS − A ≥ 14.5: considerable burden, $n = 1$ vs low, $n = 0$, node 9) (Fig. 2). With these variables, 19 out of 21 caregivers were correctly predicted by the CART model as those with considerable burden. The classification accuracy was 95%.

Discussion

The first specific aim of the present study was to evaluate the severity of caregiver burden after 10 years of continued caregiving. The findings indicate that nearly half of the caregivers experienced significant burden, predominantly related to general strain and disappointment, as these domains of the Caregiver Burden Scale (CBS) scored highest. This suggests that feelings of fatigue, overwhelmed by duties and caregiving responsibilities, combined with a sense of being trapped, are significant issues for a considerable proportion of individuals providing care for stroke patients. Due to the lack of similar studies in the available literature with such a prolonged follow-up period, to our knowledge, the results cannot be directly compared with those of other authors. Nevertheless, support for the above explanation can be found in the observations of Watanabe et al. [42], Lee et al. [43] and other authors [44], who demonstrated that 67% of informal caregivers struggle with household tasks and work-related coping, 60% encounter difficulties in mental relaxation on average, 16 years post-stroke [42], and that 51.7% experience a high caregiver burden at 6 years [43]. These limited so far empirical data might indicate the necessity of paying greater attention to caregivers' mental and physical condition during patients' medical visits, although there is still a need for more prospective longitudinal research.

The second aim of the current study was to compare the burden severity at 10 years with its levels at 5 years and 6 months after stroke. The findings show that the

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Table 2 Relationships between caregivers' and patients' characteristics and caregiver burden at Time 3 (in bold, *p*-values ≤ 0.05)

	Low burden	Considerable burden	Between groups comparison	
	n = 21	*n* = 19	test statistic	*p* value
Caregiver				
Gender, female n (%)	16 (76.2)	16 (84.2)	Fisher exact test	0.698
Age, mean (SD)	61.90 (11.99)	63.68 (10.59)	t = 0.49	0.623
Relationship to the patient, n (%)	14 (67.0)	14 (74.0)	Fisher exact test	0.736
Time spent caring/day	2.38 (2.46)	10.26 (8.31)	U = 68.0	**0.001**
Self-rated health: unsatisfied, n (%)	5 (24.0)	11 (58.0)	Fisher exact test	0.051
HADS—A, mean (SD)	5.62 (4.21)	9.42 (4.14)	U = 104.0	**0.009**
HADS—D, mean (SD)	4.38 (2.71)	8.11 (3.29)	U = 75.0	**0.001**
SOC, mean (SD)	63.71 (10.24)	55.89 (12.88)	U = 127.0	**0.050**
PSSS, mean (SD)	28.38 (5.66)	26.42 (6.98)	U = 166.0	0.319
Patient				
Gender, female n (%)	11 (52.0)	6 (32.0)	Fisher exact test	0.216
Age, mean (SD)	64.86 (11.74)	69.16 (9.23)	t = 1.27	0.209
Recurrent stroke, n (%)	3 (14)	6 (32)	Fisher exact test	0.264
SSS, mean (SD)	52.10 (5.41)	41.47 (10.91)	U = 85.5	**0.002**
BI, mean (SD)	18.14 (63.3)	12.52 (91.2)	U = 79.5	**0.001**

Abbreviations: *HADS* Hospital Depression and Anxiety Scale, *SOC* Sense of Coherence Scale, *PSSS* Perceived Social Support Scale, *SSS* Scandinavian Stroke Scale, *BI* Barthel Index, *SD* Standard deviation; *n* number
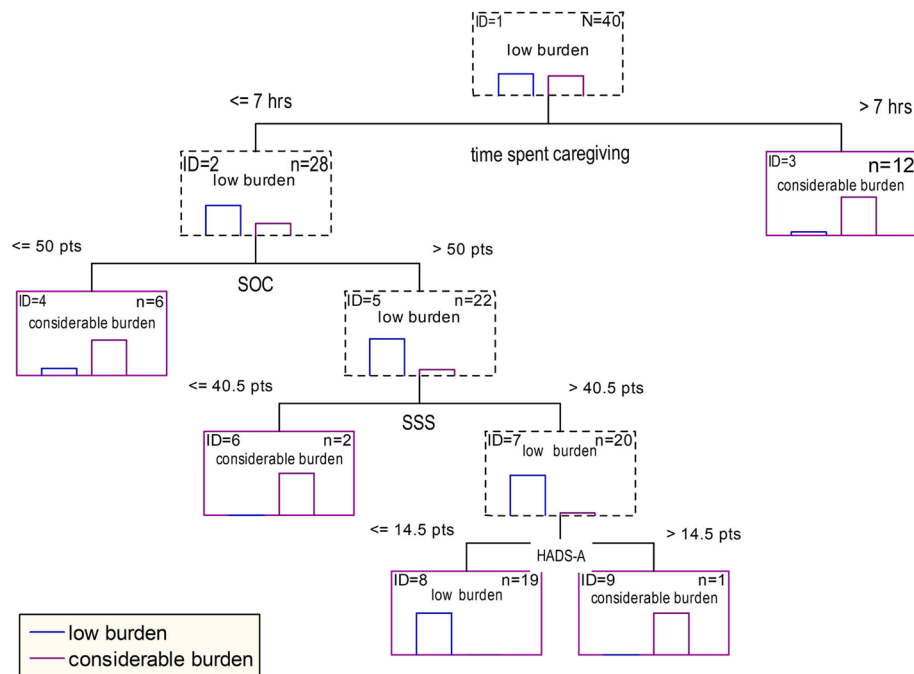

Fig. 2 The classification tree diagram showing predictors of considerable burden at T3. Abbreviations: HADS, Hospital Depression and Anxiety Scale; SOC, Sense of Coherence Scale; SSS, Scandinavian Stroke Scale; n, number

percentage of individuals who demonstrated considerable burden at 10-year follow-up was higher than the burden level reported after 5 years, and comparable to that after 6 months. A similar temporal pattern was seen for the burden level according to the mean value of the CBS score. This may suggest that the intensity of the burden fluctuates over time, being at a high level in the first months, then gradually decreasing and perhaps

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stabilising at a relatively constant level for a few years, and afterwards rising again to a level close to that to the early phase of the caregiving journey. Considering the first 5 years of observation, e.g., T1 and T2 assessments, the current results confirm those obtained earlier in the group more than twice as large as the present one when more care recipients were still alive [23]. They are also in line with the findings of other authors [21, 45, 46] and remain in accordance with "the adaptation hypothesis" [47]. The subsequent rise of burden severity at T3, in turn, could have been related to the ageing effects of both patients and caregivers, of whom the vast majority were 60 years or older. They might have, therefore, experienced physiological changes and reductions in the functioning of several bodily systems, leading to a decline in overall functional performance [48]. In the case of patients, these ageing-associated changes are likely to be accelerated, as studies on the long-term consequences of stroke have shown [24, 49, 50] and, together with original post-stroke limitations, may pose a greater challenge for the caregivers. In the case of caregivers, in turn, the potential changes linked to ageing might have reduced the physical and psychological resources required for caregiving and, consequently, raised the experienced burden. This suggestion can be supported by the fact that time spent caregiving in the studied group significantly increased, while the SOC considered as "a life source of strength and resilience" [51] decreased compared to T2 and T1. The revealed increase in burden severity could have also been partially associated with the longer-term health effects of caregiving, as reported in previous studies [44, 52–54] and detected in a supplementary analysis showing that the number of individuals reporting health problems between T1 and T3 increased from 55% to 72.5% (data not presented in the Results section).

Of the 5 CBS subscales assessed in the present work, "General strain" and "Disappointment" exhibited a similar patterns of change to the total score, providing additional support for the interpretation of the results presented above (see the first paragraph).

Although the average pattern of change in burden level from the perspective of 10 years post-stroke showed a growing trend after the period of decline, the time profile of burden was not the same for all participants, as three distinct trajectories have been identified, which confirms that informal caregiving for a stroke survivor is not "a homogenous experience". This was previously indirectly demonstrated in shorter–term studies on quality of life after stroke, which additionally showed variation in the retrieved trajectories with respect to patient-related socio-demographic [55, 56] and clinical factors [55–57]. In the present study, caregiver-level socio-demographic characteristics, such as, gender and age, did not

significantly differentiate the trajectory classes. This could have been due to the relatively small diversity in the distribution of these variables, as the large majority of caregivers were women, aligning with the literature [58], and individuals over the age of 60. Nevertheless, it does not rule out the existence of such relationships since the available evidence regarding the effect of gender and age on care burden varies in studies [46, 58, 59], and this aspect undoubtedly deserves further, more analytical investigations.

In contrast to socio-demographic variables, clinical characteristics and length of time spent caregiving significantly differed across the trajectories. The "high – low – high" and "constantly high" trajectories included caregivers who spent more hours helping per day, whose loved ones had greater neurological and functional deficits, and those who demonstrated higher levels of depressive symptoms in comparison to the "constantly low" trajectory. The first three factors, especially hours of care per day and patient's disability are frequently and consistently reported determinants or correlates of more significant burden in the longitudinal studies [21, 58, 60–63]. The same applies to depression [44, 64–66], which, according to the meta-analytical review by Loh et al. [67], affects women more often than men, resulting in a greater burden in female caregivers, although reports on this topic are conflicting [21, 46, 68].

The third and final aim of this study was to identify patient and caregiver characteristics determining the burden severity at 10 years post-stroke. The results showed that several factors differentiated persons with low and considerable burden levels. Among them, longer daily care time, weaker SOC, greater neurological deficit, and a higher level of caregiver anxiety turned out to be the predictors of considerable burden in the CART analysis, with the first two seeming to be the more important considering the number of observations in the terminal nodes. All these factors are well-known in the subject literature and repeatedly identified by the authors. According to the recent meta-analysis by Zhu and Jiang [64], including studies with reported caregiving duration from 1 to 36 months, the strength of the relationships between these factors and caregiver burden expressed by effect size ranges from small for neurological function, through moderate for time spent caring, to large for SOC and caregiver anxiety. Based on the present and previous own research [23] as well as the literature [59, 64], one can speculate that the set of predictors is relatively stable; however, their weight and position in the hierarchy may interchange depending on the phases of caregiving. Among the factors not associated with the caregiver burden, a recurrent stroke merits greater attention. The few reports on this subject suggest that caring for recurrent

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stroke patients may impose greater strain than caring for first-time stroke patients due to further functional deterioration and increased caregiver anxiety about future strokes [65]. Therefore, it is postulated that both patients and caregivers require closer post-discharge attention from health professionals [65, 69]. However, the aspect of recurrent stroke needs to be verified in further studies.

Limitations and strengths
One limitation of the study is the substantial dropout rate (73.4%) among participants, potentially introducing bias and limiting the generalizability and statistical power of the findings. Nonetheless, the high attrition rate in stroke longitudinal research is a well-known phenomenon, given that the 10-year survival rate is approximately one-third [11]. Therefore, it may be understandable that the proportion of long-term caregivers is much smaller in the short-term. It should be noted, however, that the exact number of patients who died, despite all the authors' efforts, could not be determined, as a significant portion of the participants could not be located. Another limitation is that only Polish caregivers participated in the study; therefore, the results likely do not reflect the cultural diversity of caregiving experiences, as well as the diversity arising from the differences in long-term care systems in different countries.

A positive aspect of the study is that it was conducted in the participants' homes, with data collected face-to-face from the beginning by the same experienced researchers, which potentially enhances its reliability.

Conclusions and implications
Caregivers' burden fluctuates over time and in the long-term chronic post-stroke phase poses a significant problem, as nearly half of the caregivers experience a substantial burden, which is more than in the mid-term chronic phase and comparable to that in the early phase. This problem mainly concerns individuals who spend at least 7 h a day caregiving and have weaker personal resources to cope with stress.

Since the caregiving strain extends far beyond the post-stroke adaptation phase more attention should be paid to the long–term caregivers. This is particularly important as stroke-related and caregiving-related health consequences may emerge or persist several years after the event [70, 71]. Therefore, it would be advisable for health professionals, including nurses to identify the caregivers significantly burdened with caring responsibilities, especially since family caregivers are essential partners in the nursing care for individuals with chronic health conditions.

Based on the results, the authors suggest that possible interventions should be tailored to match the caregiving stage, and for those in the long-term stage, they might include respite care, enabling caregivers to have more time for themselves. Having more personal time gives a greater opportunity for maintaining social relationships, which in turn helps foster their Sense of Coherence [72], an important resource in coping with the challenges of caregiving for the next of kin who have had a stroke.

Abbreviations
BI	Barthel Index
CART	Classification and Regression Tree
CBS	Caregiver Burden Scale
HADS	Hospital Anxiety and Depression Scale
LCA	Latent class analysis
PSSS	Perceived Social Support Scale
SD	Standard deviation
SOC	Sense of Coherence
SSS	Scandinavian Stroke Scale
T1, T2, T3	Time 1, Time 2, Time 3

Availability of data and materials
The research data in the current study are available from the corresponding author upon reasonable request.

Declarations

Ethics approval and consent to participate
The study was approved by the Bioethics Committee at the University of Medical Sciences in Poznań (no.1365/05; 32/10; 283/12). All candidates for the study were informed about the study, and those who agreed to participate gave their informed written consent. The study was carried out in accordance with the principles of the Helsinki Declaration.

Consent for publication
Not applicable.

Competing interests
The authors declare no competing interests.

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