

Stroke disease–specific quality of life trajectories and their associations with caregivers' anxiety, depression, and burden in stroke population: a longitudinal, multicentre study

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Aims

The aims of this study were to: (i) test if there are clusters of stroke survivors who experience distinct trajectories of quality of life (QOL) from hospital rehabilitation discharge to 12-month follow-up; (ii) test if any sociodemographic or clinical variables predict this class membership; and (iii) examine the associations between the clusters of stroke survivors' and their caregivers' trajectories of anxiety, depression, and burden over time.

Methods and results

A total of 415 stroke survivors and their caregivers were recruited in Italy for this 1-year, longitudinal, multicentre prospective study, filling out a survey at five time points. We found two distinct trajectories of change in stroke survivors' psychological QOL (i.e. Memory, Communication, Emotion, and Participation). The first trajectory (86% of the survivors) included those who started with greater levels of QOL and improved slightly to markedly in all psychological domains, while the second trajectory (14% of the survivors) comprised those who started with lower overall levels of psychological QOL and experienced a worsening or no changes at all in these dimensions up to 12-month follow-up. Very few clinical and sociodemographic variables at baseline predicted class membership. Finally, caregivers of those patients who experienced no change or a worsening in psychological QOL reported greater distress and burden over time.

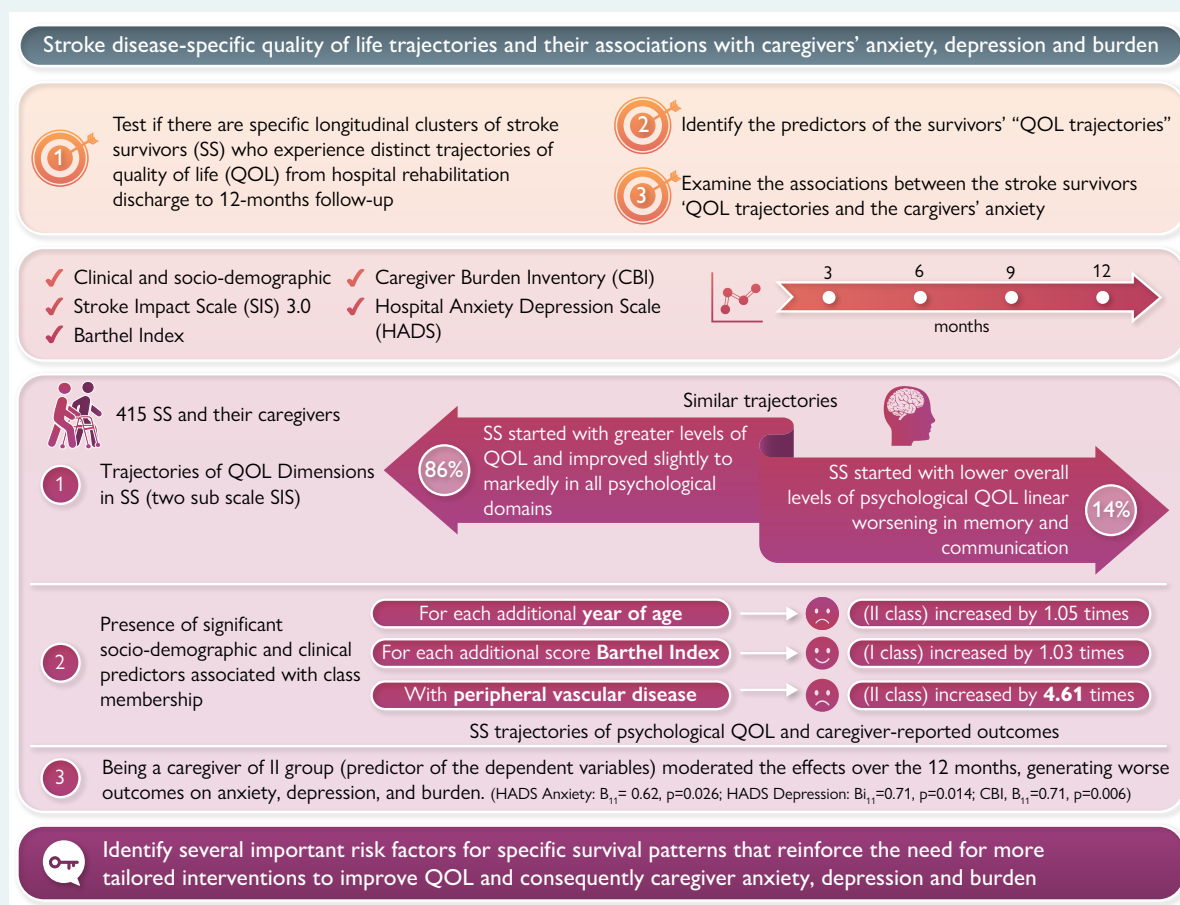
Conclusion

Our results highlight the need for more tailored interventions to improve patients' psychological QOL and consequently their caregivers' well-being. This requires a shift from a stroke survivor-centred approach to a stroke survivor- and caregiver-centred one.

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Graphical Abstract



Keywords

QOL • Stroke survivors • Caregivers • Anxiety • Depression • Burden

Novelty

- No different trajectories were identified in the physical dimensions.
- Being an older adult stroke survivor, with lower physical functioning and a comorbidity with peripheral vascular disease, results in a worsening of communication and memory; resulting in a worsening of the psychological dimension of quality of life.
- Assisting an older adult stroke survivor with limited physical abilities and peripheral vascular diseases leads to a worsening of the burden and depressive state of the caregiver.

Introduction

Stroke symptoms often predict disability and low quality of life (QOL) in stroke survivors.¹ Although improvements in stroke symptom awareness and treatment have occurred in the past decade, stroke remains a leading cause of severe long-term disability.² Indeed, after a stroke, survivors show physical, psychological, and social disabilities, such as hemiparesis and muscle weakness, which affect 88% of stroke survivors³; as well as immobility, chronic pain, sensory disturbances,⁴⁻⁶ hemianopia, aphasia, depression, and anxiety,⁵ which negatively impact QOL.

However, conflicting views regarding QOL have emerged in the stroke survivor-caregiver dyad. Several authors⁷⁻¹¹ have focused on

the stroke survivors' QOL. They expressed how important it is to investigate the post-stroke effects on the dyad over time, as there is a risk of self-isolation of the dyad if one is not psychologically and physically supported following discharge. A prospective cohort study¹² analysed stroke survivors' QOL at baseline, and at 3, 6, and 12 months after stroke survivors' discharge from the rehabilitation hospital, and observed that QOL improved during the first year after discharge. Other authors, differently, did not observe an improvement but a worsening in stroke survivors' QOL.^{11,13} This incongruence could depend on the existence of different trajectories in stroke survivors' QOL.

Furthermore, as noted by other authors,¹⁴⁻¹⁸ the stroke survivors' QOL could have an influence on their caregivers' variables, such as

anxiety, depression, or burden, and consequently caregivers' QOL. Researchers claimed^{19,20} that stroke survivors with lower physical and psychological QOL had a negative effect on caregiver anxiety, depression, and burden. Caregivers with a lower QOL stroke survivor experienced increased levels of anxiety, depression, and burden. Another study²¹ showed how the stroke survivor's degree of dependence and impairment of physical function led to a lower QOL and a subsequent increase in caregiver burden. It is well known that an increase in caregiver burden is strictly related to greater anxious and depressive symptoms.²¹ In addition, Pucciarelli et al.,²² analysed the trajectories of 244 stroke survivors' QOL in the first months after discharge from central and southern Italy rehabilitation hospitals, confirming that stroke survivors' physical function affected their QOL and consequently caregiver's anxiety and depression.

However, although stroke survivor QOL has been associated with caregiver anxiety, depression, and burden, few studies^{11,23} identified distinct trajectories in stroke survivors' QOL and observed their interdependence with caregivers' reported outcomes. For example, Pucciarelli et al.¹¹ identified three distinct trajectories of QOL in stroke survivors over 12 months after discharge from a rehabilitation hospital: high and slightly improving QOL, moderate and slightly worsening QOL, and markedly improving QOL. Specifically, they observed that when stroke patients had a high and slightly improving QOL, their caregivers had low and stable levels of anxiety, depression, and burden, which differed from those who had a moderate and slightly worsening QOL. In another longitudinal study, authors²⁴ instead found four stroke survivor QOL trajectories: high, low, recovery, and decline QOL.

The identification of specific trajectories in stroke survivors and their associations with caregiver outcomes (i.e. anxiety, depression, and burden) would be helpful for developing more tailored interventions for stroke survivors and caregivers within the first year after stroke onset. Studying the longitudinal path elucidates the gaps that emerge in the dyadic relationship between caregiver and stroke survivor over time, as expressed by some authors,^{24–27} who demonstrated how the trajectory of the QOL of the survivors, in the post-rehabilitation phase, is not always linear but undergoes changes caused by the emotional and physical state of the caregiver. This represents a gap in the literature because it is important to investigate survivors' post-rehabilitation QOL and clarify how and when certain variables positively or negatively affect the QOL of caregivers and survivors.

Therefore, the aims of this study were to: (i) test if there are clusters of stroke survivors who experience distinct trajectories of QOL from hospital rehabilitation discharge to 12-month follow-up; (ii) test if any sociodemographic or clinical variables predict this class membership; and (iii) examine the associations between the clusters of stroke survivors' and their caregivers' trajectories of anxiety, depression, and burden over time.

Methods

Participants

A 1-year longitudinal multicentre prospective study was conducted.

The inclusion criteria were a diagnosis of stroke through computed tomography or magnetic resonance imaging and returning home after discharge from a rehabilitation hospital. Stroke survivors were excluded in cases of pre-existing neurodegenerative or psychiatric diseases (e.g. multiple sclerosis), cancer or severe organ failure, previous stroke, and previous aphasia or a reduced level of consciousness. Individuals identified by the stroke survivors as primary informal caregivers (i.e. spouse/partner/child/family member or someone who provides hands-on care) were also included in the study.

Procedure

The stroke survivors and their caregivers were recruited after discharge from 1 of 20 rehabilitation hospitals located in central and southern Italy.

Those patients identified as potential participants were invited to take part in the research after being informed about the aim of the study, the data collection procedures, and the follow-up period—specifically 3, 6, 9, and 12 months after hospital release. Participants completed the research questionnaires after signing the informed consent form. The collection of data in the follow-up period took place upon appointment at participants' homes.

Materials

The Stroke Impact Scale (SIS) 3.0^{28,29} is a self-report disease-specific measure of stroke survivors' QOL and disability.^{30,31} Composed of 59 items, it includes eight subscales, namely Strength, Hand Function, (Instrumental) Activities of Daily Living, Mobility, Communication, Emotion, Memory and Thinking, and Participation. Each item is rated on a five-point Likert-type scale from 1 (an inability to complete the task) to 5 (no difficulty experienced at all). Summative scores are generated for each domain; the higher the score, the better QOL in that specific domain.

The Barthel index³² is a 10-item measure of performance in activities of daily living (ADL), namely mobility, feeding, bathing, use of a toilet, grooming, transfer, dressing, climbing stairs, and bowel and bladder control. Items are rated on an 11-point Likert-type scale (ranked 0–10), with total scores ranging from 0 to 100. A greater Barthel index indicates better performance in ADL.

The Hospital Anxiety Depression Scale (HADS)^{33,34} is a 14-item self-report questionnaire developed to investigate anxious and depressive symptoms among non-psychiatric patients. The HADS is composed of two subscales, namely Anxiety and Depression. Items are scored on a four-point Likert-type scale, with higher scores corresponding to greater levels of anxious or depressive symptoms.

The Caregiver Burden Inventory (CBI)^{35,36} is a 24-item self-report measure of the impact of burden on different aspects of a caregiver's life. The CBI evaluates five separate aspects of burden, leading to a composite total score. Items are scored on a five-point Likert scale from 0 (not at all descriptive) to 4 (very descriptive), with higher total scores indicating a greater burden for caregivers.

Data on patients' clinical and sociodemographic characteristics were also collected.

Statistical analysis

Data were initially examined through descriptive statistics [i.e. means, standard deviations (SDs), frequencies, and percentages] and tested for assumptions. All measures had a good internal consistency (α ranges: 0.73–0.97). Further, no univariate outliers were found. As for univariate normality, only HADS and CBI total scores were slightly positively skewed during all time points, and a square-root transformation corrected the violation of this assumption.

We then identified the distinct trajectories of the stroke survivors' QOL dimensions across the five time points of the study using latent class growth analysis with robust maximum likelihood estimation. This analysis allowed us to examine the first study aim. Latent class growth analysis allows for the extraction of different, longitudinal clusters of patients in a specific set of dependent variables, which in our case were the eight SIS subscales. For model selection purposes, we examined the Entropy, the Bayesian Information Criteria (BIC), and the Lo–Mendell–Rubin likelihood ratio test (LMR-LRT test) of each model, and additionally followed a practicality criterion (i.e. to have at least 5% of participant in each class). Smaller BIC values and greater entropy values (e.g. >0.80) indicate better fitting models. Further, a significant LMR-LRT test suggests that the k profile model should be rejected, and the $k-1$ profile model preferred.³⁷

Having identified different classes of patients, we then examined if any sociodemographic or clinical variables predicted class membership in one of the k groups using a logistic/multinomial regression. This allowed us to examine the second study aim. In this analysis, the dependent variable was class membership, while the independent variables were age, sex, working status (not working vs. working), educational level (less than high school vs. high school or higher), living status (alone vs. with someone), marital status (single/widowed/divorced vs. married), Barthel index, stroke type (ischaemic vs. haemorrhagic vs. transient/micro-infarct), site of the stroke (right hemisphere vs. left hemisphere vs. widespread), and the presence of hypertension, hypercholesterolaemia, diabetes without

complications, atrial fibrillation, blindness, peripheral vascular disease, thyroid disease, and chronic pulmonary disease.

Finally, we examined if being a caregiver of patients of a specific class was associated with distinct longitudinal trajectories of burden, anxious, or depressive symptoms, from baseline to 12-month follow-up, using a series of two-level hierarchical linear models (HLMs). This allowed us to test for the third and final study aim. Of note, a quadratic slope provided the best model of time for the HADS subscales, while a linear slope provided the best model of time for the CBI.

Analyses were performed with SPSS version 26, MPLUS version 8.4, and HLM version 8.1. All statistical tests were two-tailed, and a $P \leq 0.05$ was considered statistically significant.

Results

Study population

We enrolled and screened 415 stroke survivors. However, only those informal caregivers who filled out measures during at least one time point (i.e. 254 caregivers for HADS Anxiety, 253 for HADS Depression, and 249 for CBI) were included in the analyses to test the third research question. On average, caregivers were middle-aged (mean age: 52.67 ± 13.31 years) females (159, 65.2%), non-workers (129, 52.7%), and attended at least high school (137, 56.1%). The median number of hours per week spent while providing informal care was 25.

Trajectories of quality of life dimensions among stroke survivors

No distinct latent classes of participants on the eight SIS subscales were found (see [Table 1](#)). That is, on average, all patients had similar trajectories of QOL over time, while considering all dimensions of SIS at the same time.

Subsequent analyses, with SIS split into physical subscales (Strength, Hand Function, ADL, and Mobility) and psychological subscales (Memory, Emotion, Communication, and Participation), found similar results for the SIS physical domains but not the psychological ones. That is, stroke survivors had similar trajectories on physical dimensions of QOL, from discharge up to 1-year follow-up, whereas we found two distinct trajectories of change in stroke survivors' psychological QOL dimensions (see [Table 1](#) for detailed results).

The first trajectory (86% of the survivors) included those who started with greater levels of psychological QOL and improved slightly to markedly in all these domains, with this improvement decelerating over time (i.e. the quadratic term was significant and negative). The second trajectory (14% of the survivors) comprised those who started with lower overall levels of psychological QOL and experienced a linear worsening in Memory and Communication and no changes in Emotion and Participation. Means and SDs for each psychological dimension of QOL, separately for the two classes, are provided in [Table 2](#). A graphical depiction of the trajectories is provided in [Figure 1](#), while the linear and quadratic slope values and their significance are provided in [Supplementary material online, Table S1](#).

Post-event predictors of class membership

We subsequently tested for the presence of significant sociodemographic and clinical predictors of class membership (second study aim) through a multiple logistic regression ([Tables 3 and 4](#)). The full model containing all predictors was statistically significant, $\chi^2(19) = 60.333$, $P < 0.001$, explaining between 14.9% (Cox and Snell R^2) and 28.1% (Nagelkerke R^2) of the variance in class membership and correctly classifying 87.1% of cases.

As shown in [Supplementary material online, Table S2](#), for each additional year of age, the likelihood of being part of the second group

Table 1 Fit indices for the classes extracted through the latent growth mixture models in our sample of stroke survivors (N = 415)

Model and profile	Count	Proportion	Entropy	BIC	LMR-LRT	P-value
Eight SIS subscales						
One class	415	1	—	95 579.239		
Two classes	412	0.99	1	95 565.352	163.509	0.65
	3	0.01				
Four SIS physical subscales						
One class	415	1	—	48 577.292		
Two classes	412	0.99	1	48 513.734	140.137	0.24
	3	0.01				
Three classes	233	0.56	0.88	48 502.077	88.891	0.17
	179	0.43				
	3	0.01				
Four SIS psychological subscales						
One class	415	1	—	48 577.292		
Two classes	355	0.86	0.86	47 114.845	128.644	<0.001
	60	0.14				
Three classes	339	0.82	0.88	47 096.901	95.098	< 0.001
	59	0.14				
	17	0.04				

BIC, Bayesian Information Criteria; LMR-LRT, Lo–Mendell–Rubin likelihood ratio test; SIS, Stroke Impact Scale (Physical Subscales = Strength, Hand Function, ADL, Mobility; Psychological Subscales = Memory, Emotion, Communication, Participation).

Table 2 Means and standard deviation for the Stroke Impact Scale subscales during all time points (post-event, 3, 6, 9, and 12-month follow-up), separately for the two classes of patients

Group		Post-event		3 Months		6 Months		9 Months		12 Months	
		N	Mean (SD)	N	Mean (SD)	N	Mean (SD)	N	Mean (SD)	N	Mean (SD)
Communication	Class 1	354	82.93 (17.46)	284	85.65 (14.41)	235	87.55 (13.4)	220	88.08 (13.05)	202	88.58 (13.18)
	Class 2	60	53.93 (28.27)	47	47.26 (17.72)	41	47.39 (16.48)	37	43.34 (15.57)	35	42.96 (17.01)
Emotion	Class 1	353	59.65 (18.31)	284	62.36 (17.02)	235	64.26 (16.23)	221	64.62 (16.14)	202	65.73 (15.96)
	Class 2	60	45.37 (13.41)	47	47.52 (14.63)	41	47.9 (14.51)	37	47.3 (15.58)	35	48.65 (14.07)
Memory	Class 1	351	75.22 (21.08)	283	79.92 (16.76)	236	82.64 (15.68)	221	84.44 (15.19)	202	84.95 (15.26)
	Class 2	60	49.94 (30.39)	47	38.45 (18.29)	41	39.11 (16.03)	37	39.19 (14.93)	35	39.08 (18.56)
Participation	Class 1	345	49.01 (24.21)	275	54.43 (22.88)	233	58.74 (24.05)	216	62.24 (24.95)	201	63.01 (24.59)
	Class 2	55	25.57 (20.17)	45	28.4 (14.92)	41	30.72 (20.2)	36	30.9 (20.78)	35	32.23 (21.95)

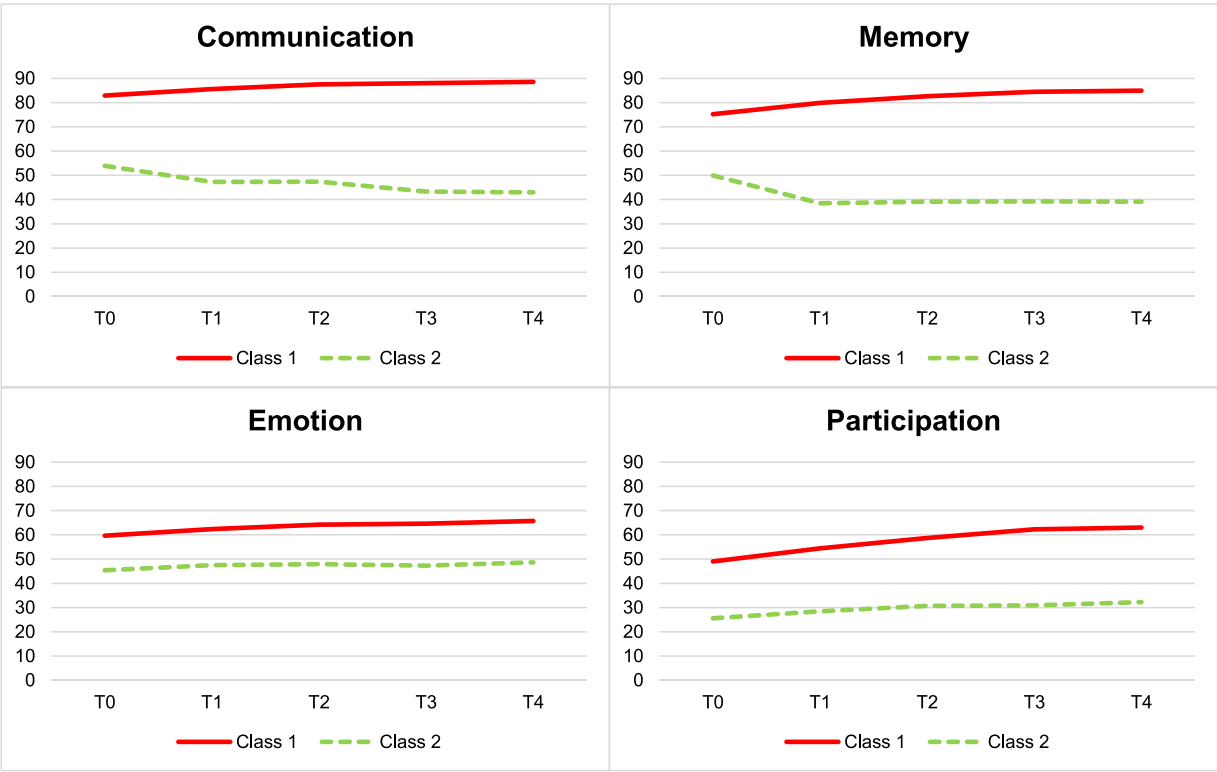


Figure 1 Longitudinal changes in the four psychological dimensions of Stroke Impact Scale, separately for the two classes of stroke survivors (Class 1, N = 355; Class 2, N = 60).

increased by 1.05 times, while controlling for all other variables in the model. Similarly, for each additional score in the Barthel index, the likelihood of being members of the first class increased by 1.03 times. Finally, those with peripheral vascular disease were 4.61 times more likely to be members of the second group. That is, we found a small number of predictors of class membership, which included older age, a lower Barthel index, and a peripheral vascular disease comorbidity. All these predictors increased the likelihood of being part of the class of patients who worsened (or experienced no improvements at all) over time in the four psychological dimensions of SIS.

Stroke survivor trajectories of psychological quality of life and caregiver-reported outcomes

Finally, we examined if class membership of stroke survivors affected the longitudinal changes in burden, anxiety, and depressive symptoms among their caregivers (third study aim), through two-level HLMs. On average, caregivers experienced linear decreases in anxious symptoms up to 12-month follow-up ($B_{10} = -0.61$, $P < 0.001$; $R^2 = 0.44$). However, burden and depressive symptoms did not significantly change

Table 3 Sociodemographic characteristics of the two classes of patients

Sociodemographic variables	Class 1 (N = 355)	Class 2 (N = 60)
Age, mean (SD)	69.69 (12.37)	76.42 (9.80)
Gender, n (%)		
Male	188 (53)	28 (46.7)
Female	164 (46.2)	31 (51.7)
Working status, n (%)		
Working	114 (32.1)	16 (26.6)
Not working	238 (67)	43 (71.7)
Educational level, n (%)		
Less than high school	250 (70.5)	47 (78.4)
High school or higher	104 (29.3)	12 (20)
Living status, n (%)		
Alone	86 (24.2)	17 (28.3)
With someone	268 (75.6)	43 (71.7)
Marital status, n (%)		
Single/widowed/divorced	150 (42.4%)	28 (46.7)
Married	204 (57.6%)	32 (53.3)

over time (HADS Depression: $B_{10} = -0.47$, $P = 0.057$, $R^2 = 0.31$; CBI: $B_{10} = -0.31$, $P = 0.086$, $R^2 = 0.05$).

Interestingly, when we entered class membership as a predictor of all the dependent variables, it significantly moderated the longitudinal changes of caregiver symptoms of anxiety, depression, and burden. That is, caregivers of those patients in the second trajectory experienced worse outcomes over time, compared with caregivers of patients in the first class (HADS Anxiety: $B_{11} = 0.62$, $P = 0.026$; HADS Depression: $B_{11} = 0.71$, $P = 0.014$; CBI: $B_{11} = 0.71$, $P = 0.006$; Table 5).

Discussion

This study sought to investigate whether there are specific longitudinal groups of patients experiencing distinct trajectories of QOL, whether there are predictors of QOL trajectories, and whether there are associations between the QOL trajectories of stroke survivors and caregiver anxiety, depression, and burden over time, from rehabilitation hospital discharge to 12-month follow-up, in a sample of 415 stroke survivors and their caregivers. Results evidenced that stroke survivors had similar trajectories on physical dimensions of QOL, from discharge up to 1-year follow-up. Interestingly, while examining the psychological dimensions, we found two distinct trajectories of change in stroke survivor QOL, which fitted the data well. To our knowledge, few studies have identified distinct trajectories of QOL in stroke survivors and analysed the interdependence with caregiver outcomes.^{11,24} However, these studies used a generic instrument to analyse the QOL trajectories of stroke survivors, while our study used a disease-specific QOL instrument. This could represent a gap because a generic QOL instrument could capture aspects of recovery related to stroke survivors' ADL, while a disease-specific QOL instrument could be more sensitive to identified changes related to stroke condition.

This study enriches the findings on similar populations reported in the literature, such as those of Pucciarelli *et al.*,¹¹ by making more 'fine-grained' analyses. First, no different trajectories in stroke survivors' physical dimensions were identified. The presence of a single trajectory

Table 4 Clinical characteristics of the two classes of patients

Clinical variables	Class 1 (N = 355)	Class 2 (N = 60)
Stroke type, n (%)		
Ischaemic	283 (79.7)	50 (83.3)
Haemorrhagic	59 (16.6)	9 (15)
Micro-infarct	10 (2.8)	1 (1.7)
Site of stroke, n (%)		
Right hemisphere	178 (50.1)	32 (53.3)
Left hemisphere	147 (41.4)	22 (36.7)
Widespread	27 (7.6)	6 (10)
Hypertension, n (%)	240 (67.6)	51 (85)
Hypercholesterolaemia, n (%)	123 (34.6)	22 (36.7)
Diabetes without complications, n (%)	106 (29.9)	24 (40)
Atrial fibrillation, n (%)	55 (15.5)	13 (21.7)
Blindness, n (%)	47 (13.2)	13 (21.7)
Peripheral vascular disease, n (%)	30 (8.5)	14 (23.3)
Thyroid disease, n (%)	39 (11)	8 (13.3)
Chronic pulmonary disease, n (%)	28 (7.9)	10 (16.7)
Total number of comorbidities, mean (SD)	1.89 (1.33)	2.51 (1.73)
Barthel index, mean (SD)	62.39 (29.42)	34.75 (27.41)

in the physical dimensions could be because stroke survivors could have similar recovery in physical dimensions. Each stroke survivor received 45–60 days of rehabilitation and experienced a similar change in physical abilities to that of the entire sample. Indeed, as described by a previous systematic review,³⁸ physical rehabilitation is an important part of treatment in stroke survivors. Physical rehabilitation was found to have beneficial effects on functional recovery, in ADL performance, and in improving motor function and gait velocity.³⁸ In addition, several studies have observed that stroke survivors usually have considerable improvement in post-stroke physical functioning due to intensive rehabilitation therapy. This could explain the reasons why we did not identify different physical trajectories in our sample.

It is interesting to note how QOL of stroke survivors has assumed two distinct trajectories about the SIS Communication, Emotional, Memory, and Participation dimensions. The first trajectory, representing 86% of survivors, included those who started with higher QOL levels and improved slightly to markedly in all psychological domains, with this improvement decelerating over time. Similarly, Communication and Emotion dimensions seem to have a slight linear improvement over 12 months, unlike Memory and Participation that seem to have a more marked improvement up to 9 months and then remain stable. The second trajectory (14% of survivors) included those who started with low overall levels of psychological QOL and experienced linear worsening of Memory and Communication, starting in the third month, and no change in Emotion and Participation.

Analysing the differences between these two groups, we observed that stroke survivors in the second trajectory were older, with lower physical functioning, and a greater peripheral vascular disease comorbidity. Being older could have had a negative impact on the trajectory in Memory and Communication. Indeed, as described by literature,³⁹ cognitive impairment manifesting after stroke is common in elderly survivors and could contribute to the clinical expression of

Table 5 Means and standard deviation for the Hospital Anxiety Depression Scale subscales and for the Caregiver Burden Inventory total score during all time points (post-event, 3, 6, 9, and 12-month follow-up) among the caregivers and separately for the caregivers of the two classes of patients

	Group	Post-event		3 Months		6 Months		9 Months		12 Months	
		N	Mean (SD)	N	Mean (SD)	N	Mean (SD)	N	Mean (SD)	N	Mean (SD)
HADS anxiety	Total	243	8.08 (4.17)	201	7.23 (4.03)	167	6.58 (3.84)	122	7.05 (4.4)	113	6.67 (4.1)
	Class 1	205	7.98 (4.35)	171	6.97 (4.03)	141	6.18 (3.6)	99	6.62 (4.56)	92	6.13 (4.06)
	Class 2	38	8.63 (3.05)	30	8.73 (3.76)	26	8.73 (4.43)	23	8.91 (3.1)	21	9.05 (3.41)
HADS depression	Total	217	7.13 (4.24)	201	6.66 (4.33)	170	6.08 (4.17)	121	6.56 (4.76)	113	6.27 (4.69)
	Class 1	181	6.92 (4.37)	171	6.31 (4.35)	144	5.54 (3.94)	98	6.09 (5)	92	5.74 (4.69)
	Class 2	36	8.19 (3.35)	30	8.63 (3.66)	26	9.04 (4.24)	23	8.57 (2.9)	21	8.62 (4.04)
CBI	Total	228	24.83 (18.62)	198	21.35 (16.51)	163	20.66 (17.77)	117	27.97 (25.81)	108	21.02 (19.48)
	Class 1	193	22.2 (16.07)	168	19.07 (15.28)	137	18.31 (16.76)	95	26.09 (26.93)	88	17.45 (17.83)
	Class 2	35	39.31 (24.5)	30	34.13 (17.53)	26	33.04 (18.1)	22	36.05 (18.7)	20	36.7 (19.06)

CBI, Caregiver Burden Inventory; HADS, Hospital Anxiety and Depression Scale.

post-stroke cognitive impairment and dementia. In addition, as described by Al-Qazzaz et al.,⁴⁰ cognitive impairment, such as memory, emotion, and communication, could be influenced by modifiable risk factors (i.e. peripheral artery disease) and non-modifiable risk factors (i.e. older age). Older survivors usually experience memory loss and cognitive slowing that could have an impact on their ADLs and their intellectual capabilities, such as thinking, communication, memory, participation, decision-making, and problem solving.⁴¹ Being older in the second trajectory could have had an impact on their cognitive abilities, and consequently on their communication and memory.⁴² Indeed, it is assumed that the onset of cognitive problems (communication and memory) generates a barrier to post-rehabilitation improvement and consequently blocks the improvement of the psychological state, such as the emotional and participatory dimensions of QOL.⁴³ Furthermore, a combination of stroke and cognitive impairment could increase the severity of physical dysfunction (Barthel index) and could explain why stroke survivors in the second trajectory had lower Barthel index scores.⁴⁴ Significant associations were also found between perceived physical functioning and participation during the first year post-stroke.⁴⁵ A recent article⁴⁶ states that cardiovascular disease (such as peripheral vascular disease) contributes to cognitive decline. This could be an aggravating factor in communication and memory problems related to QOL.

Finally, the impact of the distinct stroke survivors' QOL trajectories on caregiver variables, such as burden, anxiety, and depression, was examined. Overall, caregivers experienced linear decreases in anxiety during the first year post-stroke, while burden and depression did not significantly change over time. In the time immediately after discharge, caregivers may have higher anxiety over not knowing the consequence of stroke and they could be more worried about the home transition. The consistent decrease in caregiver anxiety over time may be related to adaption to the caregiving role. Differently, depression and burden remained stable over time. The level of depression and burden could be associated with the severity of stroke survivors' functional disability.⁴⁷ As described by a study,²¹ depression and burden were associated with prolonged care time. This may be because the long-care time occupies too much of caregivers' personal time, reducing their work, social, and entertainment time. Interestingly, when we entered class membership as a predictor of all the dependent variables, it significantly moderated the longitudinal changes in caregiver symptoms of anxiety, depression, and burden. Caregivers of stroke survivors in the second group experienced worse anxiety, depression, and burden over time, compared with caregivers of stroke survivors in the first one. As

described above, the second trajectory was significantly composed of older stroke survivors, with lower physical functioning and peripheral vascular disease. Certainly, taking care of older stroke survivors with fewer physical abilities could be more burdensome for caregivers and consequently more depressive. However, these findings were expected. Indeed, previous study¹¹ observed that caregivers who provided care to stroke patients with lower QOL had lower outcomes, such as QOL. For example, Pucciarelli et al.¹¹ in a previous study identified three distinct QOL trajectories of stroke survivors and these trajectories were strongly related to caregivers' trajectories. When stroke survivors had lower QOL, their caregivers also showed lower outcomes, differently from those who provided care to stroke survivors with higher QOL. A systematic review¹⁶ has shown that the development of depression among caregivers is a risk and stems from a lack of preparedness for the abrupt role change resulting from the stroke event, frustration, and a lack of social support. Older age, lower physical functioning, and peripheral vascular disease could be associated with greater caregiver uncertainty for the future, which could have an impact on caregiver depression and burden.⁴⁸ From the data, it appears to be natural that caregivers who assist stroke survivors with very low QOL, in relational dimensions such as memory and communication, have very high levels of stress and burden.

This study has several implications. It would be important for health professionals to understand the predictors of worsening QOL of stroke survivors to track specific preventive and supportive interventions for those survivors who could be more at risk. Fortunately, in our sample, we observed that >80% of stroke survivors had an increase in each QOL dimension. However, 14% of stroke survivors could be at risk for lower QOL over time. Knowing that survivors with a decline in Communication, Emotional, Memory, and Participation dimensions might be those with older age, lower physical functioning, and peripheral vascular disease could be crucial to providing tailored rehabilitation interventions aimed at improving these dimensions. For example, memory skills group training could improve stroke survivors' communication, emotional, memory, and participation.⁴⁹ The knowledge of someone's QOL in relation to psychological domains will be useful to doctors, people with stroke and assistants because by intercepting these problems it will give the possibility to identify people most at risk and possibly hypothesize to implement specific psychological paths that can give support to the patient and their families.

However, this study has several limitations. First, although our sample was large, it was collected from a single European country, which could limit the generalizability of the results. Second, although we

included several important survivor characteristics, we did not measure the reception of formal care, which may have improved survivor QOL over time. Future research may indeed show that there are systematic patterns in missing data in this type of research that have substantial implications for both interpretation and generalizability. In addition, we did not analyse the longitudinal interdependence between stroke survivors and caregivers. Future studies could be focused on analysing the interdependence between survivors and caregivers to better understand how these two respective elements of the dyad influence each other.

Conclusions

This study identified distinct trajectories of QOL related to stroke survivors using a disease-specific QOL instrument and observed the interdependence with caregiver outcomes, such as anxiety, depression, and burden. Our results identified several important risk factors for specific survival patterns that reinforce the need for more tailored interventions to improve QOL and consequently caregiver anxiety, depression, and burden. This requires a shift from a stroke survivor-centred approach to a stroke survivor- and caregiver-centred approach.

Supplementary material

Supplementary material is available at *European Journal of Cardiovascular Nursing* online.

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Data availability

The data underlying this article cannot be shared publicly for the reason of maintaining the privacy of individuals who participated in the study. The data will be shared on reasonable request to the corresponding author.

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