

Quality of Life of Stroke Patients and their Caregivers

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Abstract

Background: Disability following a stroke leads to deterioration in the quality of life (QoL) not only of patients, but also of their relatives. Identifying which patient-related variables have the greatest impact on caregivers' QoL will allow us to improve rehabilitation interventions.

Objective: To assess the QoL of patients after a stroke and that of their main caregivers. A secondary aim was to analyse potential relationships between patient-related variables and the most affected aspects of caregivers' QoL.

Methods: Prospective cohort study. Sociodemographic data, cognitive status, aphasia, dysphagia, and disability were evaluated 6 months after a stroke. The QoL of patients and caregivers was assessed using the 36-item Short Form Health Survey (SF-36).

Results: 157 patients and 119 caregivers were evaluated. Patients had a mean age of 70.9 ± 11.8 years and Barthel index of 77.15 ± 22.77. The caregiver was usually a woman (74%) and mean age of 58.8 ± 12.43 years. Stroke patients and caregivers perceived deterioration in their QoL, this being more marked in the case of women. Older patients obtained poorer scores in physical function. In caregivers, the SF-36 physical component summary score was lower when care recipients had poorer functional status and/or difficulty swallowing, while the mental component summary score was lower when care recipients were younger and/or male.

Conclusions: Disability of patients following a stroke has a negative impact on their quality of life and that of their main caregiver. The degree of disability and dysphagia of the care recipient have the greatest impact on caregivers' mental and physical health.

Keywords: Stroke; Rehabilitation; Quality of Life; SF-36; Caregivers

Introduction

Stroke is the leading cause of disability in adults in our setting. The current prevalence is estimated to be 6.4% among people over 70 years old, and this is expected to increase in the coming years, in turn, increasing the number of people requiring care [1]. Unlike other chronic conditions, the onset of disability caused by stroke is sudden and patients often struggle to come to terms with their new situation.

For stroke survivors, the consequences of stroke include having to depend on others to perform their activities of daily living (ADL) and disruption of their social life. This reality has a negative impact on the quality of life (QoL) of patients and also of their relatives, who usually become their main caregivers [2]. Taking on the caregiving role is a significant source of stress, increasing the caregivers' risk of developing various physical and mental health problems [3,4].

According to the current biopsychosocial model of chronic illness, the perception of patients with stroke and their caregivers concerning their own health status and QoL is particularly important, in both research and clinical practice [5]. The term health-related QoL is a concept that reflects the physical, emotional and social behaviours and attitudes of an individual, regarding their previous and current health status [6]. The assessment of QoL in patients with stroke is a complex process given the wide range of symptoms that it causes, stroke potentially affecting almost all human functions, from sphincter control to motor, cognitive and visual function, among others.

A high percentage of studies conducted to assess the QoL of stroke patients have used the generic QoL scale, the 36-item Short Form Health Survey (SF-36). This is an instrument with good psychometric properties and sensitivity to change and that can be applied to patients with different degrees of disability [7,8]. Assessing QoL implies placing importance not only on observation of the illness by clinicians but also

on patients' perception of their own condition and the perception of relatives regarding the impact of the patient's need for care.

The primary objective of this study was to assess the health-related QoL of stroke patients with disability and their caregivers. A secondary objective was to assess the potential relationships between the patient-related variables and the aspects of the caregiver QoL most affected by the caregiving role.

Methods

We conducted a multicentre longitudinal prospective cohort study including all patients who attended a follow-up appointment 6 months after their stroke, having been admitted with stroke in the subacute phase between 1 February and 30 September 2011 and subsequently discharged from one of two hospital rehabilitation units. We applied the following exclusion criteria: admission more than 6 weeks after the stroke; severe disability before the stroke, as indicated by a score ≤ 60 on the modified Barthel Index (BI); severe systemic disease; a second or further stroke, or inability to collaborate with the study; as well as declining to provide informed consent to participation in the study, or non-attendance to the 6-months follow-up appointment [9].

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At this appointment, we collected the following sociodemographic, clinical and functional data: sex, age, dysphagia (need for a soft or liquid diet due to difficulty swallowing), aphasia (as assessed with the Boston Diagnostic Aphasia Examination) [10], cognitive status (Short Portable Mental Status Questionnaire, SPMSQ) [11], depression (Geriatric Depression Scale, GDS) [12] and level of independence (modified Barthel Index) [9]. We measured QoL with the SF-36 [7,8], which is composed of 36 items grouped into 8 domains: physical functioning, role limitations due to physical problems (role-physical), bodily pain, general health perceptions, vitality, social functioning, role limitations due to emotional problems (role-emotional), and mental health. The scores in each of these eight scales range from 0 (very poor health) to 100 (optimum health). In addition, this questionnaire allows us to calculate two health summary scores, the physical (PCS) and the mental (MCS) component summary scores. We used the SF-36 v2 version of the questionnaire which is validated in Spanish [8].

In the follow-up appointment 6-months after the stroke, we also assessed the following variables concerning the main caregiver: age, sex, relationship to the care recipient (the patient), time spent caring and QoL, using the SF-36 [7,8].

This study was approved by the Clinical Research Ethics Committee for Cruces and Donostia University Hospitals (reference CREC E10/78).

Statistical Analysis

For the descriptive analysis, we used frequencies and percentages for qualitative variables, and means and standard deviations (SDs) for quantitative variables. Regarding QoL, we compared the SF-36 scores of patients and caregivers by sex and age group (<45, 45-54, 55-64, 65-74 and ≥ 75 years). Comparisons between sexes were performed using Student's t test, or the non-parametric Wilcoxon test, if the data were not normally distributed, and between age groups using analysis of variance or the non-parametric Kruskal-Wallis test, if the normality assumption was not met. The normalised SF-36 scores were also compared with values for the general Basque population [13].

The potential influence of patient-related independent variables on caregiver QoL was explored using the general linear models with the caregiver PCS and MCS scores as dependent variables, and the set of patient-related variables as independent. First, univariate models were considered to study the effect of each independent variable in the caregivers' QoL, and then, multivariate models were considered to study the effect of all variables together. The interaction between variables was also considered. In the final models, only statistically significant variables were retained.

A result was considered statistically significant when $p < 0.05$. The statistical analysis was carried out using IBM SPSS Statistics for Windows, Version 19, and SAS for Windows, Version 9.2 (SAS Institute, Inc., Cary, NC).

Results

Out of the 192 patients assessed in the follow-up appointment 6-months after their stroke, we were unable to complete the SF-36 in 35 patients due to severe language or cognitive problems, yielding a final sample of 157 patients. In addition, 38 patients attended the appointment without their main caregiver, and as a result, only 119 caregivers were interviewed. The sociodemographic characteristics of patients and caregivers assessed are summarised (Table 1).

Among patients, the mean BI score 6 months after the stroke was 75.1 ± 25.7 , and 15.9% required soft or liquid food due to difficulty swallowing, while 36.8% obtained GDS scores suggestive depression.

Characteristics	Patients (n=157)
Sex, n (%)	
Male	65 (41.4)
Female	92 (58.6)
Age (years), mean \pm SD	70.9 \pm 11.8
Dysphagia, n (%)	25 (15.9)
Aphasia, n (%)	14 (8.9)
Cognitive status (SPMSQ), mean \pm SD	1.5 \pm 2.2
Depression, n (%)	
Geriatric Depression Scale score ≥ 5	56 (36.8)
Functional status (Barthel Index), mean \pm SD	75.1 \pm 25.7
Characteristics	Caregivers (n=119)
Sex, n (%)	
Male	45 (37.8)
Female	74 (62.2)
Age (years), mean \pm SD	58.8 \pm 12.3
Relationship to care recipient, n (%)	
Partner	71 (59.7)
Son/daughter	39 (32.8)
Son/daughter-in-law	3 (2.5)
Sibling	3 (2.5)
Other	3 (2.5)
Time spent caring, n (%)	
>6 hours/day	74 (62.2)
3 to 6 hours/day	18 (15.1)
<3 hours/day	7 (5.9)
Living together	20 (16.8)

Table 1: Characteristics of patients and caregivers.

The mean age of the 119 main caregivers was 58.8 ± 12.3 years, and 62.2% were women. The main caregiver was the spouse or a child of the care recipient in 92.5% of cases (Table 1). Notably, 93% of men were cared for by women (their spouse in 73% of cases), while 55% of women were cared for by men.

Regarding QoL, patients obtained the poorest scores for physical functioning and role-physical, followed by social functioning and general health status. Women had poorer scores than men in all the SF-36 scales, the differences being statistically significant in all cases except for bodily pain and social functioning. The same trend was also apparent in MCS and PCS scores. Comparing scores by age group alone, we only observed a significant difference in physical functioning, with lower scores in patients aged 75 years old or above (Table 2).

The patients obtained lower scores in the PCS and MCS and all SF-36 scales than the general population except in the case of bodily pain, for which scores were similar. The differences were most marked in social and physical functioning and role-physical scales (Figure 1).

Caregivers obtained their poorest scores in the mental health, vitality and social functioning scales. Women obtained lower scores than men in all the SF-36 scales, as well as in the PCS and MCS, the differences being significant in the case of bodily pain, vitality, role-emotional and mental health (Table 3).

We found no significant differences as a function of age group. Caregivers obtained lower scores than the general population, the differences being the most pronounced for social functioning followed by mental health (Figure 2).

The patient-related variables independently associated with the PCS score of caregivers were patient functional status, and dysphagia. Specifically, the PCS score of the caregiver was lower when patients had

SF-36 subscales	Total (n=157)	Sex			Age group				
		Male (n=92)	Female (n=65)	p	<55 (n=15)	55-64 (n=32)	65-74 (n=37)	≥ 75 (n=73)	p
Physical functioning	37.96 ± 34.78	49.35 ± 34.07	21.85 ± 29.12	<0.001	45.00 ± 35.96	43.28 ± 36.29	50.95 ± 33.10	27.60 ± 32.19	0.003
Role-physical	26.87 ± 29.67	33.56 ± 30.87	17.40 ± 24.34	<0.001	16.25 ± 18.27	29.10 ± 31.74	34.97 ± 32.53	23.97 ± 27.82	NS
Bodily pain	73.85 ± 27.59	74.80 ± 26.02	72.40 ± 29.82	NS	65.40 ± 29.66	75.91 ± 29.01	76.76 ± 23.52	73.21 ± 28.60	NS
General health	49.89 ± 17.38	52.91 ± 18.10	45.6 ± 15.45	0.009	52.60 ± 16.95	54.91 ± 19.15	50.03 ± 17.68	47.05 ± 16.24	NS
Vitality	52.79 ± 19.51	56.25 ± 18.67	47.89 ± 19.77	0.008	47.08 ± 18.88	58.98 ± 17.39	53.21 ± 20.60	51.03 ± 19.66	NS
Social functioning	44.51 ± 32.84	44.29 ± 35.54	44.81 ± 30.53	NS	48.33 ± 35.94	41.80 ± 31.05	49.66 ± 35.90	42.29 ± 31.64	NS
Role-emotional	77.18 ± 24.91	84.69 ± 20.90	65.54 ± 26.37	<0.001	71.11 ± 23.75	82.81 ± 22.09	84.46 ± 19.06	72.26 ± 27.74	NS
Mental health	62.74 ± 17.44	66.20 ± 16.99	57.85 ± 17.00	0.003	56.33 ± 17.78	66.41 ± 14.60	66.76 ± 18.90	60.41 ± 17.28	NS
PCS	36.97 ± 10.52	39.20 ± 10.58	33.82 ± 9.67	0.001	37.15 ± 10.04	38.19 ± 11.89	39.43 ± 9.67	35.16 ± 10.28	NS
MCS	47.42 ± 9.14	48.66 ± 8.53	45.65 ± 9.73	0.042	44.63 ± 10.60	49.09 ± 6.65	48.75 ± 9.16	46.58 ± 9.68	NS

Table 2: Self-perceived health (SF-36) of patients by sex and age group (n=157).

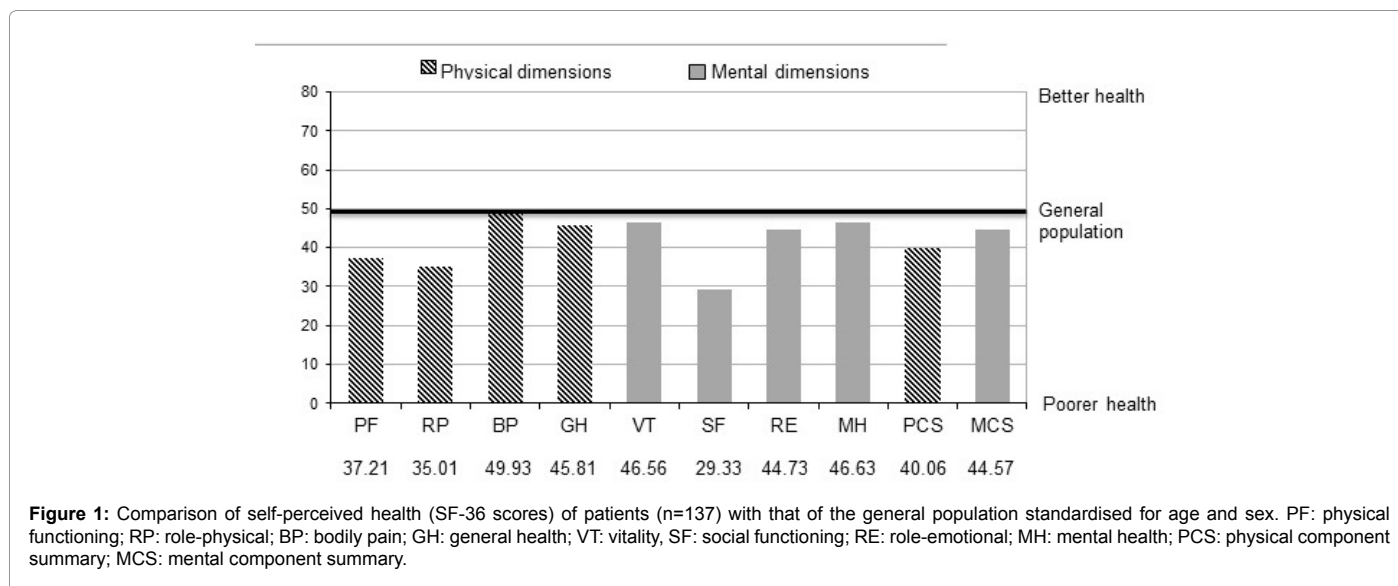


Figure 1: Comparison of self-perceived health (SF-36 scores) of patients (n=137) with that of the general population standardised for age and sex. PF: physical functioning; RP: role-physical; BP: bodily pain; GH: general health; VT: vitality; SF: social functioning; RE: role-emotional; MH: mental health; PCS: physical component summary; MCS: mental component summary.

SF-36 subscales	Total (n=119)	Sex			Age group					
		Male (n=31)	Female (n=88)	p	35-44 (n=14)	45-54 (n=27)	55-64 (n=39)	65-74 (n=23)	≥ 75 (n=16)	p
Physical functioning	90.80 ± 17.11	90.97 ± 20.99	90.74 ± 15.66	NS	96.07 ± 5.61	89.81 ± 21.86	91.28 ± 13.26	95.65 ± 6.09	79.69 ± 27.41	NS
Role-physical	71.74 ± 27.41	81.65 ± 16.53	68.25 ± 29.62	NS	82.59 ± 25.85	66.90 ± 33.15	67.95 ± 28.86	77.17 ± 17.23	71.88 ± 25.41	NS
Bodily pain	67.36 ± 28.49	76.81 ± 25.20	64.03 ± 28.97	0.033	56.43 ± 19.76	62.04 ± 28.99	71.23 ± 30.83	72.48 ± 26.14	69.13 ± 30.62	NS
General health	62.11 ± 18.89	63.71 ± 20.36	61.55 ± 18.43	NS	64.57 ± 18.41	62.44 ± 18.79	62.21 ± 18.83	64.83 ± 19.43	55.25 ± 19.56	NS
Vitality	56.78 ± 21.64	66.13 ± 20.27	53.48 ± 21.25	0.005	49.55 ± 15.98	57.41 ± 21.44	59.94 ± 24.57	57.61 ± 19.49	53.13 ± 22.13	NS
Social functioning	60.40 ± 30.42	61.69 ± 30.09	59.94 ± 30.69	NS	75.00 ± 25	61.76 ± 38.65	65.22 ± 33.49	71.88 ± 25.62	61.11 ± 28.26	NS
Role-emotional	77.80 ± 25.22	88.98 ± 16.16	73.86 ± 26.69	0.041	77.27 ± 26.11	86.76 ± 23.58	77.88 ± 25.81	85.00 ± 24.87	95.00 ± 15.81	NS
Mental health	56.43 ± 21.56	65.65 ± 18.38	53.18 ± 21.75	0.005	54.29 ± 22.09	54.07 ± 28.85	55.00 ± 25.50	61.09 ± 18.08	59.06 ± 17.15	NS
PCS	52.52 ± 7.12	53.36 ± 7.10	52.22 ± 7.14	NS	53.70 ± 5.51	51.49 ± 8.02	53.31 ± 6.9	54.08 ± 5.76	49.02 ± 8.38	NS
MCS	41.61 ± 11.30	46.33 ± 10.00	39.95 ± 11.39	NS	40.57 ± 12.52	41.14 ± 11.13	40.47 ± 12.79	43.03 ± 10.48	44.05 ± 8.66	NS

Table 3: Self-perceived health (SF-36) of caregivers, by sex and age group (n=119).

a poorer functional status and/or dysphagia (Table 4). In the case of the MCS, in addition to the aforementioned two patient-related variables, we also found that scores were significant associated with sex and age of the patient. Specifically, caregivers obtained lower MCS scores when the patient was male or in the younger age group (Table 4).

Discussion

The main objective of rehabilitation in stroke patients is to maximise their functional capacity and QoL, and relatives have an essential role in this process. It has been demonstrated that their involvement facilitates

the hospital discharge process and even contributes to patients' functional recovery [14].

Around half of the people who have had a stroke have some difficulties performing activities such as walking, dressing, bathing and showering, among other activities of daily living. The rehabilitation units that have been source of patients for this study are referral centres in the public Basque Health Service (Osakidetza) for rehabilitation of patients requiring hospitalisation after stroke. That is, these units care for stroke patients who have moderate-to-severe disability that makes them unable to return to their own homes during the acute phase of

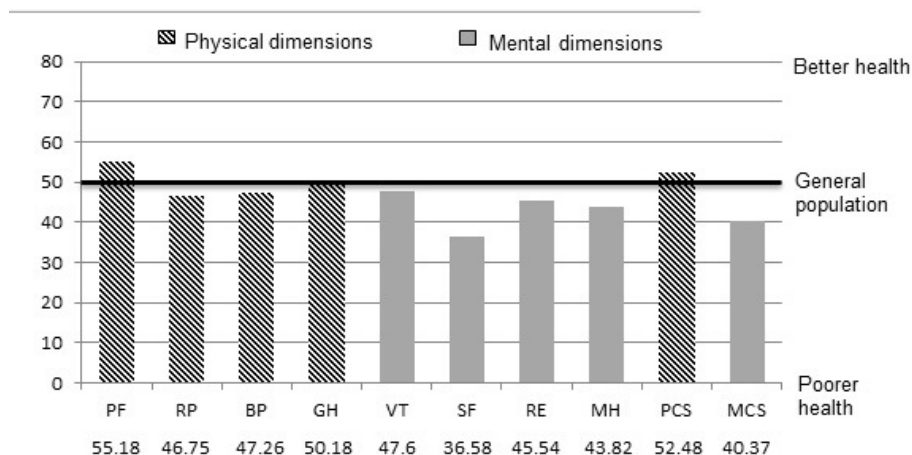


Figure 2: Comparison of self-perceived health (SF-36 scores) of caregivers (n=119) with that of the general population standardised for age and sex. PF: physical functioning; RP: role-physical; BP: bodily pain; GH: general health; VT: vitality; SF: social functioning; RE: role-emotional; MH: mental health; PCS: physical component summary; MCS: mental component summary.

Patient-related variables	n	Physical Component Summary score				Mental Component Summary score			
		Univariate		Multivariate		Univariate		Multivariate	
		β parameter	p	β parameter	p	β parameter	p	β parameter	p
Sex									
Male	74	Ref.	–			Ref.	–	Ref.	–
Female	45	-0.90	0.5042			8.10	0.0001	7.42	0.0004
Age (years)									
<75	72	Ref.	–			Ref.	–	Ref.	–
≥ 75	47	-1.81	0.1774			5.20	0.0139	4.36	0.0286
Aphasia 6 months after stroke									
No	85	Ref.	–			Ref.	–		
Yes	34	-1.76	0.2240			-2.85	0.2171		
Dysphagia 6 months after stroke									
No	93	Ref.	–	Ref.	–	Ref.	–	Ref.	–
Yes	26	-3.38	0.0317	-3.10	0.0445	-6.73	0.0071	-4.72	0.0408
Barthel Index 6 months after stroke									
Low level of dependence+independence (90-100)	35	Ref.	–	Ref.	–	Ref.	–	Ref.	–
Complete+severe+moderate dependence (0-90)	84	-3.71	0.0090	-3.50	0.0126	-5.64	0.0130	-7.57	0.0004
Cognitive status (SPMSQ)									
Normal cognitive status 0-2)	74	Ref.	–			Ref.	–		
Mild cognitive impairment (3-4)	9	1.03	0.6746			1.85	0.6426		
Moderate-severe cognitive impairment (≥ 5)	17	-0.35	0.8520			-2.83	0.3510		
Depression (Geriatric Depression Scale)									
Absence of depression (<5)	53	Ref.	–			Ref.	–		
Suggestive of depression (≥ 5)	40	0.08	0.9545			0.25	0.9132		

Table 4: Impact of patient-related variables on caregiver quality of life (SF-36) (n=119).

the disease. Hence, the results of our study cannot be extrapolated to all stroke patients, but only to survivors with the greatest degree of disability. In our study, the profile of a typical patient was that of a 71-year-old with a BI score of 75, indicating moderate disability, 6 months after having had a stroke. In the case of the main caregiver, the typical profile was that of a middle-aged woman, the spouse or daughter in the majority of cases, consistent with the profile of caregiver reported in other studies in Spain [15,16] and indicating that caregiving is not equally shared among family members.

As was to have been expected, some patients, almost a fifth (18.23%), did not complete the SF-36 due to severe language or cognitive problems. In these cases, some researchers use a “proxy”, a person that lives and participates in the daily care of the patient, to complete the questionnaire

on the patient’s behalf. It is well documented, however, that the responses of a proxy tend to underestimate patient quality of life, in particular in relation to emotional issues [5]. A specific questionnaire developed for assessing QoL in stroke patients with aphasia has been adapted for Spanish speakers but not yet validated [17]; once validated, it would be of interest for future research given the high percentage of patients to which it would apply.

In our series, patients had a poor self-perceived health status, as reflected in low scores across the SF-36 scales, and women are significantly more severely affected, having poorer QoL scores in both mental and physical components, in agreement with in other studies [18-20]. Physical functioning and role-physical are the SF-36 scores that were most affected, as would be expected given that we assessed patients with a degree of disability.

In the light of our results, we can confirm that stroke has a pronounced effect on the QoL of both patients and their caregivers, in both physical and mental domains, as found in other studies [5,21]. Older patients report stroke having a greater impact on physical functioning. Further, female caregivers had a significantly lower QoL than male caregivers, similar to the findings of other authors [4,22]. In a sample of 215 caregivers, Marco et al. [23] found that the negative impact of caring for a stroke patient is greater in middle-aged female caregivers, and that depression and musculoskeletal pain in the caregiver, time spent caring and degree of disability of the care recipient are influential factors in this deterioration in QoL. Regarding pain, reported by around 30% of stroke patients [23], our results are striking in the sense that its occurrence and impact on QoL 6 months after the stroke is even higher in caregivers than the care recipients themselves, who obtained pain scores similar to those of members of the general population of the same age and sex.

Caregivers' PCS scores are lower when patients have a poorer functional status, as observed in previous studies [2,5]. Dysphagia in particular was found to be a predictor of caregiver QoL, in both physical and mental domains. Care recipients having difficulty to eat or drink safely implies that caregivers have to change the texture of food and drinks they provide, to avoid aspiration, and also makes them concerned about safety and fearful of potential complications, such as malnutrition and respiratory diseases. Franceschini et al. [24] assessed the impact of neurological deficits on the QoL of patients 1 year after stroke, and they reported that dysphagia, present in 5.7% of their patients, did not play a notable role in the deterioration in QoL. Their sample was not comparable to that of our study, however, given that their patients had better functional status. Very few studies have assessed the experience of caregivers in terms of the emotional effect of living with individuals who have difficulty swallowing. One exception is the work of Johansson et al. [25,26] which gathers data on this type of experience of caregivers and emphasized the importance of appropriate information and training as the best way of supporting them.

The MCS score of caregivers was lower when the care recipient is male or relatively young. Regarding age, it is plausible that it is more emotionally difficult to accept disability in a young relative, than caring for an individual of advanced age, who can be expected to have poorer health. In contrast, however, other authors such as Patel et al. [23] observed a greater reduction in QoL when the care recipient was female and older.

In the opinion of Franzhen et al. [27], it is essential to strive to improve the psychological health of caregivers and minimise potential medical complications to ensure that patients can continue to be cared for at home. Depression in patients has also been described by some authors as a variable that contributes to a poorer QoL, both in patients and caregivers [28]. In our study, however, patient depression did not seem to have a substantial impact on the QoL of the caregiver. Persson et al. [22] performed a 7-year follow-up of 248 patients and their caregivers and found that the age of the caregiver and the physical disability of the patient influence the physical component of caregivers' health, while patient depression, cognitive deficiency and disability have a greater impact on the mental component. Kwok et al. [29] found patient depression to be the factor with the greatest adverse effect on QoL 1 year after stroke, and proposed self-help group exercises and social activities to enhance their social life.

The contribution of rehabilitation, with a multidisciplinary approach, to improving the QoL of stroke patients may be attributable to this type of care being focused on functional improvement and responding to the needs of caregivers during rehabilitation, through

the provision of appropriate information and training in physical, functional and emotional domains that may have been affected by the stroke. According to Katona et al. [30], a reduction in the risk of falls and greater awareness of changes in the patient's emotional status during rehabilitation have a positive impact on the future QoL of patients.

The SF-36 scale enables comparisons of QoL between different illnesses and with the general population. Further, the stratification of SF-36 scores by age means that we are also able to distinguish differences in the effects of stroke as a function of age. The SF-36 scale is not, however, immune to criticism, given that it does not appropriately reflect the overall mental and physical health of stroke patients, excluding, for example, the impact on their sex life and ability to communicate with others [31]. In this regard, other stroke-specific scales, such as the Stroke Impact Scale (SIS) [32] or the Stroke-Specific Quality of Life Scale, ECVI-38 [33,34] may be useful given their greater sensitivity to specific health problems. As in other studies [35], we have opted for assessing QoL at 6 months after the stroke, since it is considered that patients tend to have become functionally stable by this time. Some researchers, however, have used longer follow-up periods and have observed marked decreases in QoL [36,37].

These study findings should encourage a reflection to implement different initiatives intended to approach specific deficits affecting the quality of life of the caregivers. Thus, all carers of patients with dysphagia should receive recommendations by the speech therapists to ensure safe and effective nutrition. We know from experience that through the information and the training given to carers to cope better with this specific disability, through a variety of modalities (stroke schools, websites, bedside care training, etc.) are helping to provide confidence and security in its handling. In addition, regular monitoring of patients in our departments, attentive to possible complications, contributes to increase their calm due to their perception that the health care system looks after them. In this sense, the recommendations made by the Panel of experts in stroke are very interesting [38].

This study sought to characterise the health status of stroke patients and their caregivers, and to assess the impact of the associated disability on the QoL of patients and their families. It is particularly important that caregivers themselves feel supported, providing them with appropriate emotional support as well as preparing and training them to live with disability [39,40]. Family caregivers play a key role in the stroke recovery process, and hence, it is useful to find strategies to improve the management of the situation to minimise the detrimental effect of caring on caregivers' QoL.

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