

The use of a machine learning approach to predict perceived stress and quality of life among caregivers of stroke patients

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Abstract. *Background and aim of the work:* Caregivers of stroke survivors play a crucial role in providing home care, which often involves significant stress and impacts their quality of life. Various factors, including caregiving responsibilities, work-life balance, and social support, influence caregivers’ well-being. This study aims to examine the quality of life and stress levels among caregivers of stroke survivors. *Research design and Methods:* A comprehensive survey was conducted using personalized questions and two validated instruments: the SF-36 Health Survey and the Perceived Stress Scale (PSS-10). Additionally, the SF-36 was employed for training an Artificial Intelligence (AI) model to predict perceived stress levels, generating estimated scores on the PSS-10. *Results.* The findings indicate that caregivers experience significant stress and have low quality of life scores. The AI model successfully predicted perceived stress levels, demonstrating the utility of combining health surveys with AI techniques for efficient stress assessment. *Conclusions:* Understanding the experiences and well-being of caregivers is essential for developing targeted interventions to support them. Improving caregivers’ quality of life can enhance the overall management of stroke-affected patients. (www.actabiomedica.it)

Key words: caregivers, stroke, quality of life, perceived stress, SF-36, PSS-10, Artificial Intelligence

Introduction

Stroke represents the second leading cause of death and the third leading cause of global disability (1–5), accounting for 9–10% of all deaths and causing disability in over 80 million individuals (6). In Italy, there are 90,000 hospitalizations due to cerebral stroke, of which 20% are recurrent cases. Only 25% of

survivors fully recover, while 75% live with some form of disability; half of these have such severe deficits that they lose their independence (7). This catastrophic event needs immediate hospitalization for precise diagnosis, prevention/treatment of cardiac, respiratory, and metabolic complications, as well as early initiation of rehabilitation. Medical advancements have increased the number of survivors, but many experience

disabilities and complications such as falls, pneumonia, infections, depression, social isolation, physical/cognitive deficits, and recurrences even after a year (8,9).

Chronic disability, especially among those over 65, leads to dependence on caregivers, often cohabiting, for daily routines (3). This transforms caregiving into a full-time commitment, impacting the caregiver's psychophysical and social well-being (10). During post-stroke care, caregivers face stress related to both the patient (functional/neurological/emotional status) and themselves (time of care/health/emotional state/stress coping/social support). Gender, age, relationship, and profession have minimal impact (11).

The caregiver's well-being affects the assisted person's recovery. Studies show that support from professionals and close individuals can alleviate the burden (12,13). Family caregivers often lack the skills to address physical, cognitive, emotional, and behavioral issues (14), leading to depression, psychophysical deficits, reduced quality of life, and isolation (8). This also affects employment, causing reduced working hours, resignations, or early retirements (15).

Caregiver challenges hinder high-quality care, impacting the survivor's recovery and increasing the risk of other conditions/mortality, for both the patient and the caregiver (16). The caregiver's quality of life decreases compared to the general population, with anxiety, concerns about the patient's health, and rehabilitation costs. Studies demonstrate that caregivers have an incidence of mental health disorders similar to or higher than patients (15). During the COVID-19 pandemic, the challenges for stroke survivors and their caregivers intensified significantly. Lockdowns and healthcare system strains restricted access to routine medical care, rehabilitation services, and social support networks (17–21). The fear of virus transmission further isolated stroke survivors and their caregivers, exacerbating feelings of loneliness and stress. Caregivers had to navigate the complexities of protecting the stroke survivor from infection while managing their ongoing medical needs. Additionally, the interruption of in-person therapeutic and support services shifted more responsibility onto caregivers, often without adequate preparation or resources. This led to increased psychological stress, anxiety, and burden among caregivers, complicating their already demanding roles.

The pandemic highlighted the critical need for resilient healthcare strategies that can maintain continuous care for stroke survivors and support for caregivers, even in times of global health crises.

In literature, there are few studies that have analyzed the interaction among the patient, family members, and the home care worker, as well as the training of the latter (22).

In this study, we examined the quality of life and stress in a population of caregivers assisting stroke survivors at home through a questionnaire.

By identifying key factors associated with caregivers' stress and quality of life, this study not only contributes to a deeper understanding of the challenges faced by caregivers but also serves as a crucial foundation for developing tailored strategies. These strategies, informed by empirical evidence, aim to enhance caregivers' well-being and improve the overall quality of care for stroke patients. The results also have potential implications for shaping health policy and caregiver support programs, ensuring that interventions are both effective and targeted.

Methods

Study design and methodology

From September 2022 to March 2023, a survey was administered among a population of stroke caregivers. One-hundred and one subjects have agreed to participate in the study. The survey was conducted by means of an anonymous questionnaire distributed on a voluntary basis. All sections of the questionnaire were computerized using a preset form from the Google Drive platform, and the study was conducted through electronic dissemination. Facebook groups of various types and Instagram pages used for publishing computerized questionnaires were contacted. The sampling used was (virtual) snowball sampling until data saturation.

Survey instrument

Assessment was conducted using a questionnaire containing 'ad hoc' questions to gather information on

caregivers' training and prior knowledge before starting caregiving, pre-stroke lifestyle, and post-stroke consequences for the patient. In addition to these customized questions, two validated questionnaires were included to assess quality of life and stress.

In detailed, the questionnaire consists of 3 sections: The first section (17 items) comprises socio-demographic data of both caregivers and patients, including gender, age, nationality, marital status, level of education, employment status, relationship between caregiver and patient, presence of children, and type of stroke. Additionally, it gathers information related to the caregiving, such as the amount of care time provided per day and the number of years of assistance. The second section (20) includes information about caregivers' knowledge and training about the stroke before caregiving and the difficulty they encountered once they started providing assistance. The third section (29) investigates the lifestyle of the care recipients before stroke and the psycho-physical consequences of it. In addition to the above, we have included two other validated questionnaires: the 36-item short-form health survey (SF-36) (23) and the Perceived Stress Scale (PSS-10) (24).

The SF-36 questionnaire provides a general assessment on different aspects of life and health. It consists of 8 health domains: physical functioning (PF); role limitations because of physical problems (RP); bodily pain (BP); general health (GH); vitality (VT); social functioning (SF); role limitations because of emotional problems (RE); and mental health (MH). SF-36 scores were calculated using the methods set out by Ware et al. (24) and range from 0 to 100, with higher scores indicating a better health state.

To measure perceived stress, the PSS-10 questionnaire (24) was used, assigning a score from 0 to 40 based on 10 questions. It is a validated and reliable questionnaire to measure stressful experiences and responses to stress over the previous 4 weeks (24). Of the three versions (4-, 10-, and 18-item measurements), the PSS-10 is considered the one with the most satisfactory psychometric properties (25). Each item in the questionnaire is rated on a 5-point Likert scale (0 = never, 1 = almost never, 2 = sometimes, 3 = fairly often, 4 = very often). Scores for the four positively stated items (Items 4, 5, 7, 8) are scored in a reverse

manner. Higher scores indicating higher levels of perceived stress.

Statistical analysis

The answers of all respondents to the questionnaire items were reported using descriptive statistics. Continuous variables were summarized using the mean and standard deviation (SD), and categorical variables were summarized using frequencies and percentages. For the two validated questionnaires, descriptive statistics for the item responses, such as the item median, standard deviation, skewness, floor, and ceiling effects, and 95% confidence intervals, were assessed and reported for each scale score. Cronbach's alpha was used to measure the scale internal consistency reliability. To determine the factors that influence the anxiety of caregivers, a one-way ANOVA was performed. The statistical analyses were conducted for all qualitative and quantitative variables using MATLAB software. Statistical significance level was set at $p < 0.05$.

Machine learning

To optimize the evaluation process and save time and resources, the SF-36 questionnaire was also used as feature set to train an artificial intelligence (AI) model. This model was able to predict the level of perceived stress, providing an estimated score on the PSS-10 scale. Consequently, in addition to providing an estimation of the quality of life based on SF-36 questionnaire data, the model allows obtaining an indication of the stress level that participants would have reported if they had completed the PSS-10 questionnaire.

Similarly to the approach used by Choi (26), the respondents were divided into two groups based on the PSS-10 scale: high stress ($n=48$, 47%) vs. low stress ($n=53$, 53%). For this purpose, the PSS-10 items were summed, and each total score was then divided by its mean value ($M = 22.79$). Subsequently, results below the mean value were coded as "1" (representing "low stress"), while results above the mean value were coded as "2" (representing "high stress"). A supervised Machine Learning approach was then employed to classify caregivers into high vs. low stress using a supervised approach based on the classes obtained from

the PSS-10 scale and using the SF-36 items as features to train the classifier. To ensure fairness in the classification process, the features were normalized to a range of 0-1 using min-max normalization on the training set, and the same normalization parameters were applied to the test set samples. Three different classifiers (Naive Bayes, decision trees, and support vector machine) were tested. The training process followed a Hold-Out cross-validation scheme, with 80 percent of the samples used for training the network. To assess classification quality and determine an optimal threshold value for the model classifier output, statistics such as the ROC curve were used. Based on the definition of an optimal work point on the ROC curve, a binary classifier was obtained. Additionally, various metrics of performance were used, including accuracy, average precision-recall, confusion matrix, and the Area Under the Curve (AUC) from the ROC curve. Computation was performed with the MATLAB software.

Ethical considerations

The study received approval from the Ethics Committee (Protocol 5252 dated 30/06/2022). The study was conducted in accordance with the Declaration of Helsinki. Prior to participation, all caregivers were provided with detailed information about the study's purpose, procedures, potential risks, and benefits. Informed consent was obtained from each participant, ensuring their voluntary participation and their right to withdraw from the study at any time without consequence. Consent was documented through a signed form, which participants could either submit electronically or in person, depending on their preference.

Results

Sample demographics and baseline characteristics

A total of 101 stroke caregivers agreed to participate in the study. Baseline characteristics were collected and reported in Table 1. Responders were 75% females and 25% males. The mean age of the participants was 47.69 years (SD = 15.84), with a range of 12-75 years.

Half of the sample was from Italy while the other half had different nationality. Most of the participants (43%) had completed higher secondary education, and 37% had a university degree. Sixty-two percent of the participants were either students or workers, while 39% were unemployed or retired. Forty-two percent of the surveyed caregivers have been taking care of their care recipient for more than 1 year, with 21% of them providing care for over 10 years. Additionally, almost half of them (40%) dedicate more than a full workday (12-24 hours) to their care recipient. In most cases (44%) caregivers assist the wife or husband, while in 32% of cases, the caregiver is a parent or child (17%). On the other hand, the section concerning care recipients, the respondents reported that they were predominantly male (59%), most of whom were married (67%), had children (78%), and had a high school diploma (36%). Ischemic stroke was the most common reason for stroke (81%). Sixty-two percent of the care recipients were unemployed or retired or lost their jobs because of the stroke, while 5% were disabled.

Questionnaire items

The questionnaire items were evaluated for all respondents and data were collected (Tables 2-5).

Table 2 investigates caregivers' knowledge about stroke and the sources from which they obtained information about the disease. It also examines the number of hours of care the caregiver provides per day and whether they have received adequate training and information about managing the patient at home. Eighty percent of the respondents had heard about stroke before their care recipient's diagnosis. Surprisingly, 50% of them state that they had rarely or never heard about it at school or in a healthcare setting (42%), with most of the information coming from their family (26%), mass media (18%), or friends (16%). Even more astonishingly, 60% of caregivers declared they had not been informed by the health care facility or received an informational pamphlet (70%) about the possible critical care issues and aspects they would face once they returned to home care. Moreover, more than half of the respondents (56%) declared that they had not been involved in the care process of the care recipient during the hospitalization period, and only 15% of the

Table 1. Sampling characteristics of all respondents (socio-demographics data and information about the caregiver and the care recipients) (n=101).

Baseline Characteristics	N (%)
CAREGIVER SOCIO DEMOGRAPHIC DATA	
Gender	
Female	76 (75)
Male	25 (25)
Age	
Range	12-75
Mean	47.69
SD	15.84
Nationality	
Italian	51 (50)
Non-Italian	50 (50)
Marital status	
Married	64 (63)
Single	28 (28)
Separated/Divorced	8 (8)
Widower	1 (1)
Education level	
No title	0
Junior high school diploma	10 (10)
High school graduation	10 (10)
Higher Diploma	44 (43)
Graduate Diploma	19 (19)
Postgraduate training	18 (18)
Employment status	
Caregiver	2 (2)
Civil servant	20 (20)
Private employee	26 (26)
Freelancer	7 (7)
Unemployed	17 (17)
Retired	22 (22)
Student	7 (7)
Invalid	0
How long have you been caring for the caregiver?	
1-3 months	16 (16)
6-12 months	22 (22)
1-3 years	42 (42)
>10 years	21 (21)
How many hours of daily assistance do you devote to the caregiver?	
3	22 (22)
4-6	18 (18)
7-12	21 (21)
12-24	40 (40)
SOCIO-DEMOGRAPHIC DATA OF THE ASSISTED PERSON	
Gender	
Female	41 (41)
Male	60 (59)

Baseline Characteristics	N (%)
Marital status	
Married	68 (67)
Single/Celibate	10 (10)
Separated/Divorced	3 (3)
Widower	20 (20)
Education level	
No title	15 (15)
Junior high school diploma	16 (16)
High school graduation	8 (8)
Higher Diploma	37 (36)
Graduate Diploma	15 (15)
Postgraduate training	10 (10)
Employment status	
Caregiver	0
Civil servant	8 (8)
Private employee	16 (16)
Freelancer	8 (8)
Unemployed	9 (8)
Retired	54 (53)
Student	0
Invalid	5 (5)
missing	1 (1)
The patient lost the job due to the stroke	
No	65 (64)
Yes	36 (36)
Does the patient have children?	
No	22 (22)
Yes	79 (78)
Degree of relationship between the Caregiver and the Patient	
Parents	15 (15)
Son/Daughter	17 (17)
Brother/Sister	4 (4)
Wife/Husband	44 (44)
Comrade	4 (4)
Son-in-law/Daughter-in-law	2 (2)
Grandfather/Grandmother	2 (2)
Father-in-law/Mother-in-law	1 (1)
Aunt/Uncle	1 (1)
Grandson	2 (2)
Cousin	1 (1)
Friend	2 (2)
Acquaintance	5 (5)
missing	1 (1)
Type of stroke	
Hemorrhagic stroke	19 (19)
Ischemic stroke	82 (81)

Table 2. Information about caregivers' knowledge and training about the stroke before caregiving (n=101)

	N (%)		N (%)
Before the diagnosis, had you ever heard of stroke?		During your hospitalization period, did the health care staff involve you in the care process?	
No	20 (20)	No	56 (56)
Yes	81 (80)	Yes	45 (45)
If you answered YES to the previous question, in what area did you hear about it?		Please indicate what difficulties you experienced in the early stage of the disease (at home)	
MASS MEDIA		Lack/absence of information on disease outcomes.	
Always	1 (1)	Very	53 (53)
Often	17 (17)	Quiet	27 (27)
Occasionally	43 (43)	Little	12 (12)
Rarely	21 (21)	Not at all	9 (9)
Never	19 (19)	Lack of/absence of information about health care providers who can deliver home care.	
FAMILY		Very	56 (56)
Always	5 (5)	Quiet	25 (25)
Often	21 (21)	Little	11 (11)
Occasionally	25 (25)	Not at all	9 (9)
Rarely	21 (21)	Lack/absence of training on medication management and daily physical activities.	
Never	29 (29)	Very	39 (39)
SCHOOL		Quiet	21 (21)
Always	1 (1)	Little	30 (30)
Often	8 (8)	Not at all	11 (11)
Occasionally	26 (26)	Lack/absence of health care from Doctors and Nurses, Home Health Care Workers	
Rarely	15 (15)	Very	43 (43)
Never	51 (50)	Quiet	30 (30)
FRIENDS		Little	19 (19)
Always	1 (1)	Not at all	9 (9)
Often	15 (15)	Lack/absence of psychological support both during his or her inpatient stay and at home.	
Occasionally	33 (32)	Very	62 (62)
Rarely	28 (28)	Quiet	21 (21)
Never	24 (24)	Little	9 (9)
SANITARY		Not at all	9 (9)
Always	13 (13)	Which of the following is a cause of the stress caused by your client's illness? (You may also indicate more than one cause)	
Often	16 (16)	Need to be assisted in all life activities.	51 (22)
Occasionally	30 (29)	Need to be understood in the expression of needs Inadequacy of aids and spaces at home.	48 (21)
Rarely	18 (18)	Lack of aids to cope with disability.	41 (18)
Never	24 (24)	Lack of territorial nursing and medical supports in the home	33 (15)
Before caring for the caregiver, did you attend any training?			53 (23)
No	86 (85)		
Yes	15 (15)		
Prior to discharge from the health care facility where your patient was admitted, were you informed about possible critical care issues at home?			
No	60 (60)		
Yes	41 (41)		
Did the health care facility provide you with an informational pamphlet about the aspects to be monitored at home?			
No	70 (70)		
Yes	31 (31)		

	N (%)
Are there territorial agencies that help you at home to assist your family member?	
No	69 (68)
Yes	32 (32)
If you answered yes to the previous question, they are:	
Public	21 (21)
Privates	11 (11)
Missing	58 (58)
Do you think there are territorial interventions to be made to help you on a daily basis?	
No	29 (29)
Yes	72 (72)
Do you think transporting these patients to the hospital for follow-up visits is difficult?	
No	26 (26)
Yes	75 (75)
Do you believe, however, that nursing or home support figures could help you on a daily basis in caring for your family member?	
No	15 (15)
Yes	86 (86)
In the moments of greatest distress, whom did you ask for help?	
Work colleagues	9 (6)
Friends	33 (22)
Family	61 (40)
Psychologist/psychotherapist	8 (5)
General practitioner	13 (9)
Medical specialist	8 (5)
Spiritual father	3 (2)
None	17 (11)
Were you taking antidepressant/ anxiolytic drugs before caring for your caregiver?	
No	87 (87)
Yes	14 (14)
Do you currently take antidepressant/ anxiety medications?	
No	74 (74)
Yes	27 (27)

subjects attended a training course before taking care of the care recipient.

In the initial phase of home disease management, caregivers reported numerous difficulties, including a

lack of information on disease outcomes, medication management, healthcare assistance, and psychological support (>50%). Incredibly, 68% of the respondents stated that there are no local institutions to assist the family member at home. Only the remaining 32% are aware of public (21%) and private (11%) organizations. Many caregivers indeed believe that it is necessary to establish external territorial interventions (72%) and introduce healthcare support personnel at home to help with daily care activities (86%). Even transporting care recipients to the hospital for check-ups seems challenging (75%). All these factors inevitably lead to stress for caregivers, of whom 13% have started taking antidepressant/anxiolytic medications only after beginning caregiving. Furthermore, in times of distress, many of them turn to family members (40%) or friends (22%), while the figure of a psychologist or primary care and specialist doctor represents only a very small proportion (5%, 14% respectively).

Table 3 shows the lifestyle of the care recipient before the onset of the stroke to identify potential responsible risk factors and the presence of psycho-physical consequences of the stroke, which could have also led to the patient's hospitalization. Interestingly, more than half of caregivers (53%) had hypertension before stroke. Other risk factors stated to a lesser extent include cigarette smoking (23%), being sedentary (31%), and the presence of previous medical conditions (26%).

Even more impactful, however, are the psycho-physical consequences manifested following a stroke. Disability was experienced by 63% of those who had a stroke, with an additional 18% requiring hospitalization because of it. Among these individuals, nearly half (47%) experienced severe disability. Other consequences include impaired balance (70%) and falls (45%), high blood pressure (65%), sleep (54%) and eating disorders (35%), dysphagia (44%), dehydration (35%), pressure ulcers (30%), and pneumonia (19%). At the psychological level, caregivers reported various conditions felt by their care recipients. These include anxiety (75%), fear (74%), mood alterations (72%), difficulty accepting the illness (72%), depression (71%), cognitive impairment (67%), feelings of inadequacy (61%), confusional states (61%), psychomotor agitation (56%), reduced state of consciousness (54%), and

Table 3. Lifestyle of the care recipients before stroke and the psycho-physical consequences.

	N (%)		N (%)
LIFESTYLE OF THE PATIENT BEFORE THE STROKE		DEPRESSION	
Could you describe your recipient's lifestyle before the acute event?		Presence	62 (62)
HYPERTENSION		Presence, with hospitalization	9 (9)
No	32 (32)	Absence	30 (30)
Yes	53 (53)	INADEQUACY	
I don't know.	16 (16)	Presence	55 (55)
ALCOHOL ABUSE		Presence, with hospitalization	6 (6)
No	89 (89)	Absence	40 (40)
Yes	5 (5)	STATES OF CONFUSION	
I don't know.	7 (7)	Presence	48 (48)
DRUG ABUSE		Presence, with hospitalization	13 (13)
No	96 (96)	Absence	40 (40)
Yes	2 (2)	PSYCHO-MOTOR AGITATION	
I don't know.	3 (3)	Presence	40 (40)
CIGARETTE SMOKING ABUSE		Presence, with hospitalization	16 (16)
No	75 (75)	Absence	45 (45)
Yes	23 (23)	MOOD ALTERATIONS	
I don't know.	3 (3)	Presence	63 (63)
SEDENTARY		Presence, with hospitalization	9 (9)
No	63 (63)	Absence	29 (29)
Yes	31 (31)	REDUCED STATE OF CONSCIOUSNESS	
I don't know.	7 (7)	Presence	41 (41)
PRESENCE OF PREVIOUS PATHOLOGIES		Presence, with hospitalization	13 (13)
No	57 (5)	Absence	47 (47)
Yes	26 (26)	COGNITIVE IMPAIRMENT	
I don't know.	18 (18)	Presence	52 (52)
HAD NO RISK FACTORS		Presence, with hospitalization	15 (15)
No	49 (49)	Absence	34 (34)
Yes	30 (30)	SLEEP DISORDERS	
I don't know.	22 (22)	Presence	51 (51)
PSYCHOPHYSICAL CONSEQUENCES OF THE STROKE		Presence, with hospitalization	3 (3)
Please indicate which of these consequences occurred and which of these listed generated a hospitalization of the patient		Absence	47 (47)
POST-STROKE DISABILITY		EATING DISORDERS	
Presence	63 (63)	Presence	27 (27)
Presence, with hospitalization	18 (18)	Presence, with hospitalization	8 (8)
Absence	20 (20)	Absence	66 (66)
FEAR		DEHYDRATION	
Presence	62 (62)	Presence	27 (27)
Presence, with hospitalization	12 (12)	Presence, with hospitalization	8 (8)
Absence	27 (27)	Absence	66 (66)
ANXIETY		DYSPHAGIA	
Presence	65 (65)	Presence	30 (30)
Presence, with hospitalization	10 (10)	Presence, with hospitalization	14 (14)
Absence	26 (26)	Absence	57 (57)
		PNEUMONIA	
		Presence	7 (7)
		Presence, with hospitalization	12 (12)
		Absence	82 (82)

	N (%)
ALTERATIONS IN BALANCE	59 (59)
Presence	11 (11)
Presence, with hospitalization Absence	31 (31)
FALLS	32 (32)
Presence	13 (13)
Presence, with hospitalization Absence	56 (56)
ARTERIAL HYPERTENSION	
Presence	51 (51)
Presence, with hospitalization	14 (14)
Absence	36 (36)
DIFFICULTY ACCEPTING THE DISEASE	
Presence	64 (64)
Presence, with hospitalization	8 (8)
Absence	29 (29)
DIFFICULTY UNDERGOING TREATMENT	
Presence	30 (30)
Presence, with hospitalization	13 (13)
Absence	58 (58)
DECUBITUS INJURIES	
Presence	20 (20)
Presence, with hospitalization	10 (10)
Absence	71 (71)
IF DISABILITY HAS OCCURRED, INDICATE THE DEGREE	
Severe	47 (47)
Moderate	42 (42)
Mild	9 (9)
missing	3 (3)

difficulty undergoing treatment (43%), which are the most common, and many of them also required hospital intervention with hospitalization.

Table 4 and Table 5 refer to the SF-36 and PSS-10 questionnaire responses and their relative percentage, respectively. Frequency distribution of scores in percent were summarized in Figure 1.

Quality of life and stress score analysis

The part A of Table 6 presents the descriptive statistics and characteristics of the score distributions for the entire SF-36 questionnaire.

A very poor health has been reported by caregivers, with value scores ranging from 27 to 61%. The highest score is given to PF (61%), followed by RE (51%),

Table 4: The 36-item short-form health survey (SF-36) questionnaire items.

Impact Of Caregiver's Quality Of Life	N (%)
In general, you would say that your health is:	
Excellent	8 (8)
Very good	9 (9)
Good	27 (27)
Passable	43 (43)
Poor	14 (14)
Compared to a year ago, how would you rate your overall health now?	
Definitely better than a year ago	18 (18)
A little better now than a year ago	0
About the same as a year ago	31 (31)
A little worse now than a year ago	28 (28)
Definitely worse now than a year ago	24 (24)
The following questions are about some activities that you might perform in the course of any given day. Does your health currently limit you in performing these activities?	
Physically demanding activities, such as running, lifting heavy objects, playing strenuous sports.	
Yes, it limits me a lot.	38 (38)
Yes, it partially limits me.	36 (36)
No, it doesn't limit me at all	27 (27)
Moderate strenuous activities, such as moving a table, vacuuming, playing bocce ball, or taking a bike ride.	
Yes, it limits me a lot.	26 (26)
Yes, it partially limits me.	35 (35)
No, it doesn't limit me at all	40 (40)
Lifting or carrying shopping bags	
Yes, it limits me a lot.	18 (18)
Yes, it partially limits me.	36 (36)
No, it doesn't limit me at all	47 (47)
Climb a few floors of stairs.	
Yes, it limits me a lot.	25 (25)
Yes, it partially limits me.	35 (35)
No, it doesn't limit me at all	41 (41)
Going up one floor of stairs	
Yes, it limits me a lot.	21 (21)
Yes, it partially limits me.	33 (33)
No, it doesn't limit me at all	47 (47)
Bending, kneeling, or stooping	
Yes, it limits me a lot.	30 (30)
Yes, it partially limits me.	32 (32)
No, it doesn't limit me at all	39 (39)
Walking a kilometer	
Yes, it limits me a lot.	23 (23)
Yes, it partially limits me.	32 (32)
No, it doesn't limit me at all	46 (46)

Table 4 (Continued)

Impact Of Caregiver's Quality Of Life	N (%)
Walk a few hundred meters.	
Yes, it limits me a lot.	21 (21)
Yes, it partially limits me.	25 (25)
No, it doesn't limit me at all	55 (55)
Walk about one hundred meters.	
Yes, it limits me a lot.	16 (16)
Yes, it partially limits me.	25 (25)
No, it doesn't limit me at all	60 (60)
Bathing or dressing yourself.	
Yes, it limits me a lot.	18 (18)
Yes, it partially limits me.	20 (20)
No, it doesn't limit me at all	63 (63)
In the past four weeks, have you experienced the following problems at work or in other daily activities due to your physical health?	
Reduced time spent on work or other activities.	
No	30 (30)
Yes	71 (71)
You have achieved less than you would have wanted.	
No	25 (25)
Yes	76 (76)
Had to limit certain types of work or other activities.	
No	28 (28)
Yes	73 (73)
Had difficulty in performing work or other activities, (e.g., struggled more)	
No	27 (27)
Yes	74 (74)
In the past four weeks, have you experienced the following problems at work or in other daily activities due to your emotional state (such as feeling depressed or anxious)?	
Reduced time spent on work or other activities.	
No	24 (24)
Yes	77 (77)
You have achieved less than you would have wanted.	
No	30 (30)
Yes	71 (71)
Had a lapse in concentration at work or in other activities.	
No	27 (27)
Yes	74 (74)

Impact Of Caregiver's Quality Of Life	N (%)
In the past four weeks, to what extent has your physical health or emotional state interfered with normal social activities, with family, friends, neighbors, and groups you belong to?	
Very much	20 (20)
Very	21 (21)
A little bit	33 (33)
Slightly	14 (14)
Not at all	13 (13)
How much physical pain have you experienced in the past four weeks?	
Very strong	17 (17)
Strong	12 (12)
Moderate	26 (26)
Mild	13 (13)
Very slight	15 (15)
None	18 (18)
In the past four weeks, to what extent has pain hindered you in your usual work (both at home and away from home)?	
Very much	16 (16)
Very	20 (20)
A little bit	22 (22)
Slightly	16 (16)
Not at all	27 (27)
The following questions relate to how you have felt in the past four weeks.	
Answer each question by choosing the answer that is closest to your case. How long in the last four weeks have you felt:	
Lively and bright	
Always	4 (4)
Almost always	7 (7)
Long time	12 (12)
Part of the time	28 (28)
Almost never	36 (36)
Never	14 (14)
Very agitated	
Always	12 (12)
Almost always	23 (23)
Long time	12 (12)
Part of the time	33 (33)
Almost never	13 (13)
Never	8 (8)
So down in the dumps that nothing could have cheered you up.	
Always	8 (8)
Almost always	21 (21)
Long time	16 (16)
Part of the time	26 (26)
Almost never	17 (17)
Never	13 (13)

Impact Of Caregiver's Quality Of Life	N (%)
Calm and serene	
Always	5 (5)
Almost always	12 (12)
Long time	17 (17)
Part of the time	27 (27)
Almost never	30 (30)
Never	10 (10)
Full of energy	
Always	3 (3)
Almost always	9 (9)
Long time	14 (14)
Part of the time	27 (27)
Almost never	27 (27)
Never	21 (21)
Discouraged and sad	
Always	15 (15)
Almost always	22 (22)
Long time	15 (15)
Part of the time	32 (32)
Almost never	13 (13)
Never	4 (4)
Exhausted	
Always	16 (16)
Almost always	28 (28)
Long time	21 (21)
Part of the time	21 (21)
Almost never	11 (11)
Never	4 (4)
Happy	
Always	5 (5)
Almost always	13 (13)
Long time	11 (11)
Part of the time	31 (31)
Almost never	26 (26)
Never	15 (15)
Tired	
Always	25 (25)
Almost always	27 (17)
Long time	21 (21)
Part of the time	22 (22)
Almost never	3 (3)
Never	3 (3)
In the past four weeks, how long has your physical health or emotional state interfered with your social activities, family, friends?	
Always	19 (19)
Almost always	23 (23)
Part of the time	35 (35)
Almost never	17 (17)
Never	7 (7)

Impact Of Caregiver's Quality Of Life	N (%)
Choose the answer that best describes how true or false the following statements are.	
I seem to get sick a little easier than others.	
Completely true	13 (13)
Largely true	27 (27)
I don't know.	30 (30)
Largely false	17 (17)
Completely false	14 (14)
My health is like other people's health.	
Completely true	5 (5)
Largely true	30 (30)
I don't know.	36 (36)
Largely false	19 (19)
Completely false	11 (11)
I expect that my health will deteriorate.	
Completely true	15 (15)
Largely true	38 (38)
I don't know.	23 (23)
Largely false	16 (16)
Completely false	9 (9)
I enjoy excellent health.	
Completely true	7 (7)
Largely true	33 (33)
I don't know.	20 (20)
Largely false	22 (22)
Completely false	19 (19)

but in general, all the values are below 50%, denoting very poor quality of life. Skewness ranges between -0.45 and 0.52, with most values positive, demonstrating again a low health score. The caregiver group's lowest mean score is for the RP and BP scales (27% each), with positive skewness (+1.02). However, the same scales have shown ceiling effects (18.19% and 24.42%, respectively), indicate that a good percentage of caregivers reported having good physical function and being able to handle the responsibilities and tasks related to patient care without severe limitations. The internal consistency reliability for all items was 0.94. The minimum Cronbach's alpha was greater than 0.60. For 5 out of 8 scales, Cronbach's alpha was greater than 0.80 and for both the PF scale and RE scale was greater than 0.90, satisfying Nunnally's criterion of 0.7 (27). These measure of consistency were also better than those reported in other similar studies (28–30).

The part B of the Table 6 shows the descriptive statistics and characteristics of the score distributions

Table 5. Perceived Stress Scale (PSS-10) responses and relative percentages.

PERCEIVED STRESS SCALE	N (%)
In the past month, how often have you felt out of sorts because something unexpected happened?	
Never	23 (23)
Almost never	23 (23)
Sometimes	21 (21)
Quite often	17 (17)
Very often	17 (17)
In the past month, how often have you felt that you were not able to have control over the important things in your life?	
Never	13 (13)
Almost never	15 (15)
Sometimes	27 (27)
Quite often	21 (21)
Very often	25 (25)
In the past month, how often have you felt nervous or stressed?	
Never	6 (6)
Almost never	16 (16)
Sometimes	28 (28)
Quite often	28 (28)
Very often	23 (23)
In the past month, how often have you felt confident about your ability to manage your personal problems?	
Never	17 (17)
Almost never	26 (26)
Sometimes	34 (34)
Quite often	14 (14)
Very often	10 (10)
In the past month, how often did you feel that things were going as you said?	
Never	20 (20)
Almost never	28 (28)
Sometimes	40 (40)
Quite often	10 (10)
Very often	3 (3)
In the past month, how often have you felt that you could not stand behind all the things you had to do?	
Never	7 (7)
Almost never	20 (20)
Sometimes	31 (31)
Quite often	13 (13)
Very often	30 (30)

In the past month, how often did you feel that you were able to control what irritates you in your life?	
Never	13 (13)
Almost never	27 (27)
Sometimes	33 (33)
Quite often	16 (16)
Very often	12 (12)
In the past month, how often did you feel you mastered the situation?	
Never	15 (15)
Almost never	33 (33)
Sometimes	26 (26)
Quite often	11 (11)
Very often	6 (6)
In the past month, how often have you been angry about things that were out of your control?	
Never	14 (14)
Almost never	14 (14)
Sometimes	28 (28)
Quite often	21 (21)
Very often	24 (24)
In the past month, how often have you felt that the difficulties are being were accumulating to a point where you could not overcome them?	
Never	12 (12)
Almost never	20 (20)
Sometimes	26 (26)
Quite often	15 (15)
Very often	28 (28)

for the entire PSS-10 questionnaire. The PSS-10 score ranged from 8 to 40 (SD 1.97), denoting a certain variability, with the mean of 23. The internal consistency is greater than 0.70.

To determine the factors that influence the anxiety of caregivers, univariate analysis was performed. Factors such as gender, care time per day, relationship to the patient, occupational status but also some psycho-physical consequences of stroke and difficulties of the caregiver in managing the patient at home, were found to be significantly associated with high levels of stress (PSS-10 scale), low quality of life (SF-36 scale), or both. These results are shown in Table 7.

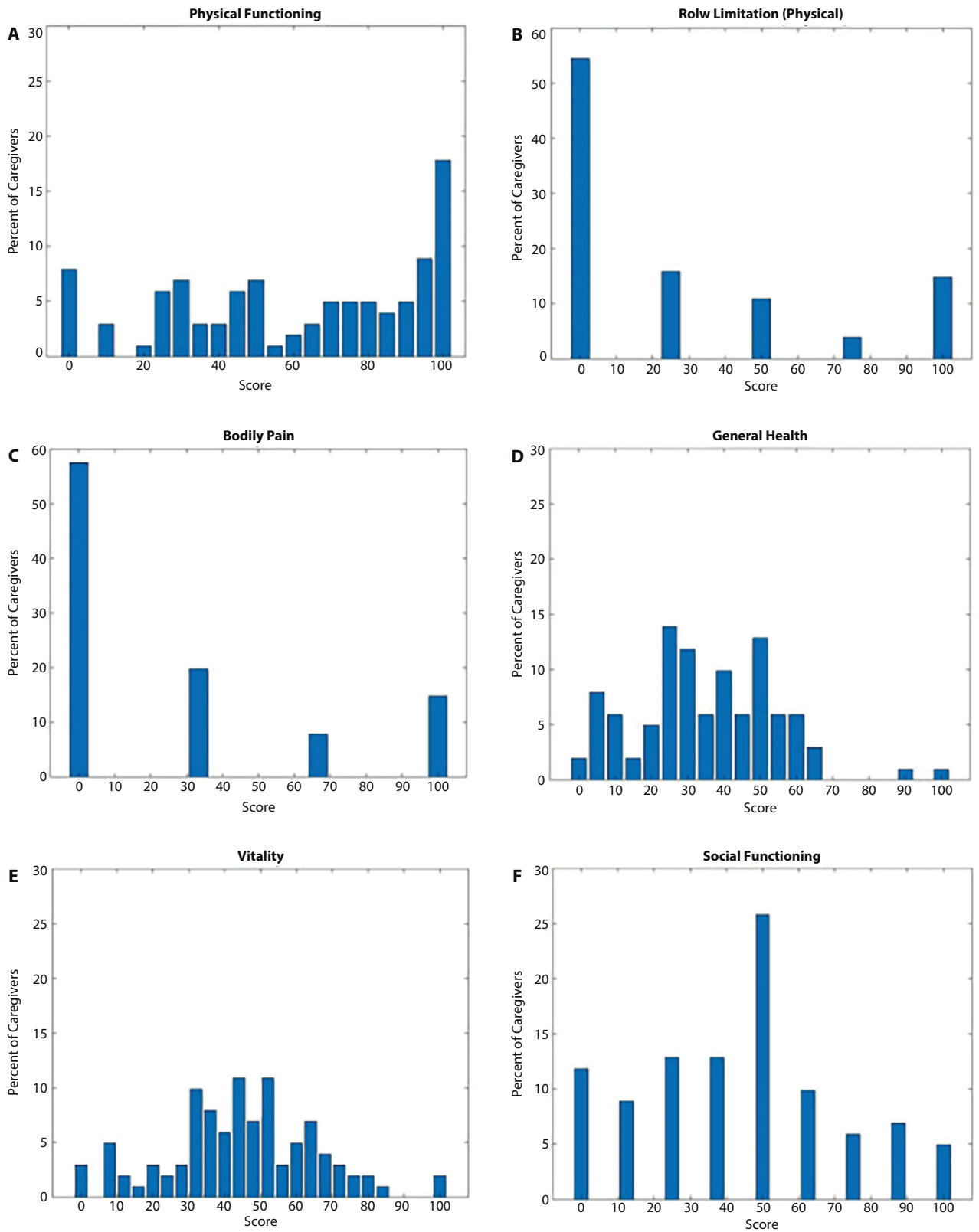


Figure 1. Frequency distribution of scores.

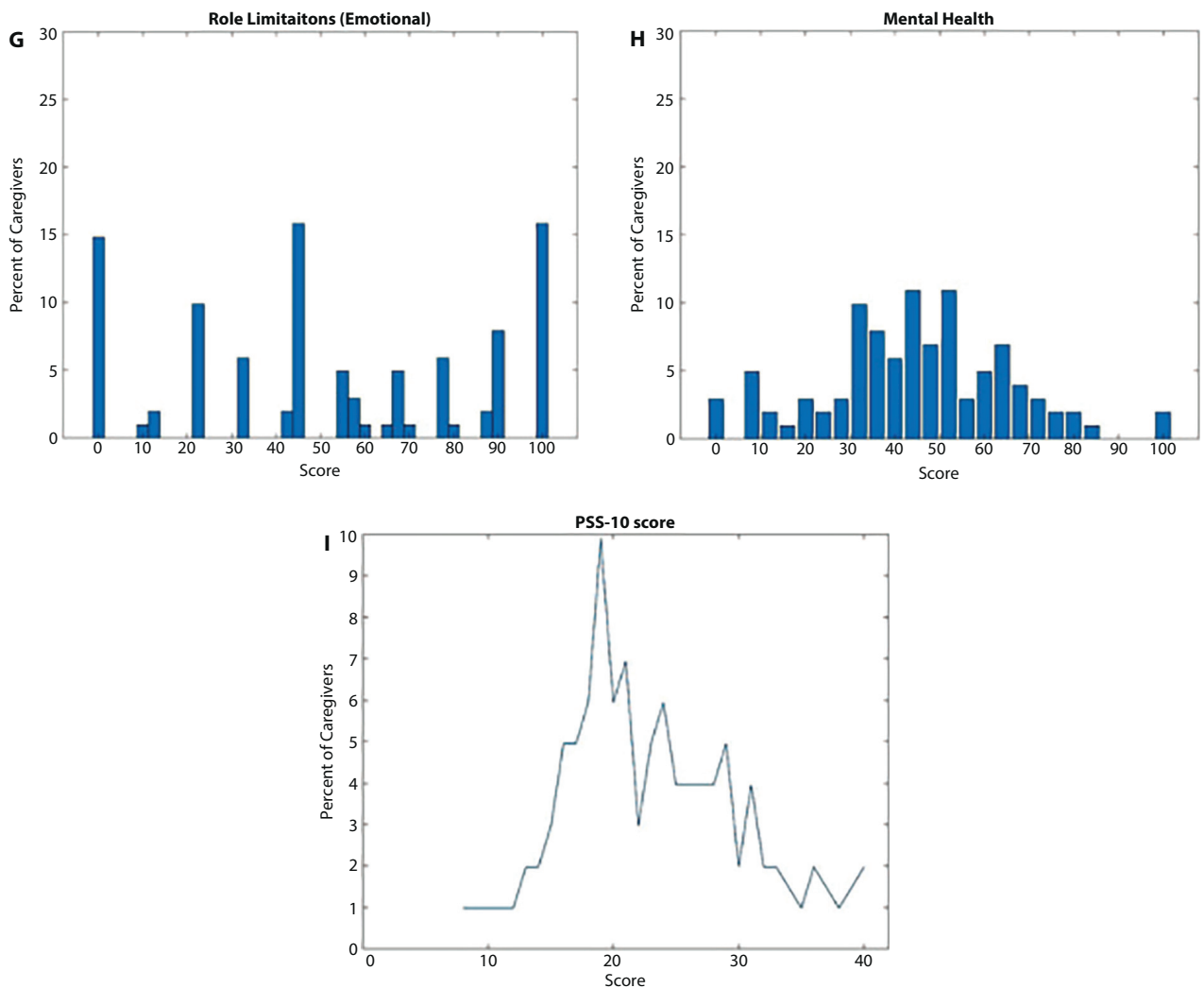


Figure 1. (continued)

A Machine Learning approach was then employed to classify caregivers into high vs. low stress using a supervised approach based on the classes obtained from the PSS-10 scale. The best results were obtained with the Naïve Bayes classifier. The trained model correctly identified 85% of PSS-10 score, achieved a sensitivity of 100% and a specificity of 73% (Table 8). The AUC from the test ROC curve was 0.94 (Figure 2).

Conclusions

The present study aimed to investigate the experiences and challenges faced by caregivers of stroke

patients and analyze the impact of caregiving on their quality of life and stress levels. The assessment was conducted through a questionnaire that included tailored questions to gather information about caregivers' prior training and knowledge before starting caregiving, pre-stroke lifestyle, and post-stroke consequences for the patients and caregivers. In addition to these personalized questions, two validated questionnaires, SF-36, and PSS-10 respectively, were also used to evaluate quality of life and stress.

The demographic characteristics of the sample revealed that most caregivers were female (75%), with an average age of approximately 48 years. This aligns with previous research indicating that caregiving is often

Table 6. Descriptive statistics of score distributions for SF-36 and PSS-10 questionnaire. Cronbach's alpha was used to measure the scales' internal consistency reliability.

PART A: Scale SF-36	No. of items	Score	95% CI	Median	SD	% floor†	% ceiling‡	Skewness	Cronbach's α^* Total items = 0.94
Physical Functioning (PE)	10	61	61.27-61.41	65	1.13	4.60	2.34	-0.45	0.9
Role Physical (RP)	4	27	27.12-27.33	0	1.06	6.81	18.19	1.02	0.8
Bodily Pain (BP)	3	27	26.55-26.91	0	1.57	8.91	24.42	1.02	0.7
General Health (GH)	4	35	35.00-35.20	35	1.00	0.87	4.70	0.52	0.7
Vitality (VT)	5	45	44.56-44.78	48	1.27	1.39	2.38	0.17	0.8
Social Functioning (SF)	2	44	43.41-43.97	50	2.00	4.95	9.65	0.16	0.8
Role Emotional (RE)	2	51	50.81-51.17	45	1.31	11.14	8.17	0.08	0.9
Mental Health (MH)	5	45	44.94-45.45	40	2.90	3.96	3.01	0.23	0.6
PART B: Scale PSS-10	No. of items	Score	95% CI	Median	SD	% floor†	% ceiling‡	Skewness	Cronbach's α^*
PSS-10 items	10	23	22.90-23.14	23	1.97	1.05	2.10	-0.18	0.72

†Percentage of subjects with worst possible score.

‡Percentage of subjects with best possible score.

*Measure of internal consistency.

undertaken by middle-aged individuals, especially women (31). Interestingly, our study's sample included caregivers from various nationalities, underscoring the global nature of caregiving and the universality of the challenges faced.

Stroke can lead to a decrease in self-sufficiency and an increase in care needs. Its sudden onset is overwhelming for family members who often find themselves taking on the role of caregivers within a few days of the event (32). Therefore, there is a need to educate and involve caregivers from the early stages of the care process. In our study, while a significant portion of caregivers had heard about stroke before their care recipient's diagnosis, the majority had rarely or never encountered information about stroke in educational or healthcare settings. This implies a potential gap in disseminating crucial information about stroke prevention, recognition, and management. Our findings concerning caregivers' knowledge about stroke and their sources of information suggest that there is room

for improvement in stroke education. This is in line with other studies, which report that family caregivers of stroke patients express the need for education and information (33).

Approximately 44% of stroke survivors are discharged directly home without hospital or outpatient rehabilitation services (34). Often, home discharge represents a second, unexpected crisis for both patients and their family caregivers (34). The caregiver's top priority is undoubtedly to be informed about the nature of the condition, which arises so suddenly and violently that it leaves family members of stroke patients undoubtedly unprepared and powerless. The information needs highlighted in the study by Lutz et al. (32) focus on recovery prognosis, how to provide assistance after discharge, and the available resources that could aid in post-discharge care. Our study highlighted the lack of training and preparation provided to caregivers by healthcare professionals, both before and after assuming caregiving responsibilities.

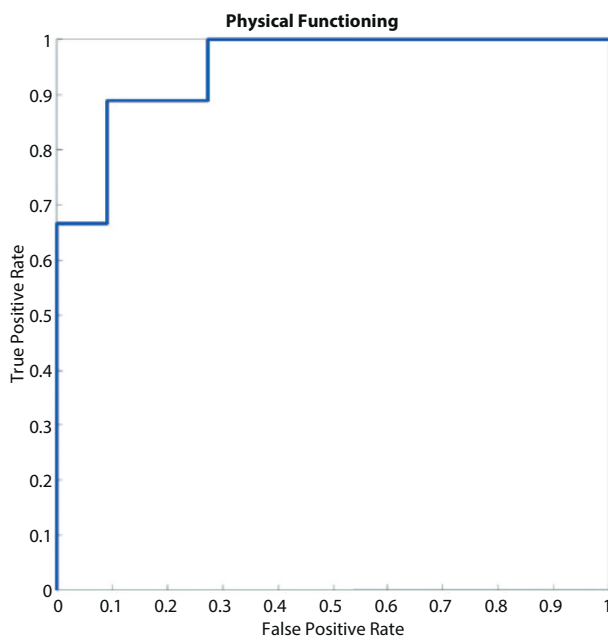
Table 7. Univariate analysis of the stress scores of caregivers (n=101). A p-value <0.05 was considered statistically significant (*p<0.05; **p<0.01; ***p<0.001).

Influencing factor	Group	n (%)	$\mu \pm SD$	SF-36 F (p-value)	PSS-10 F (p-value)
Age	≤ 50	45(44)	41.26±30.48	2.34 (0.07)	1.04 (0.37)
	51-60	37(37)	56.45±27.89		
	61-70	16(16)	67.81±20.30		
	≥71	3(3)	40.00±15.71		
Gender	Male	25(25)	53.28±30.35	2.29 (0.13)	4.26 (0.04*)
	Female	76(75)	50.25±29.11		
Education level	Primary school	20(20)	48.70± 18.04	0.13 (0.93)	0.54 (0.65)
	Secondary school	44(43)	47.90±30.38		
	Degree	19(19)	36.94±30.24		
	Post-graduate	18(18)	75.94±21.72		
Care Time	≤ 3 hours	22(22)	45.40±28.30	5.52 (<0.001***)	2.66 (0.05*)
	4-6 hours	18(18)	42.61±28.74		
	7-11 hours	21(21)	49.61± 30.62		
	12-24 hours	40(40)	58.57±28.61		
Relationship to the patient	Husband/Wife	44(43)	62.27±26.31	2.23 (0.03*)	1.32 (0.25)
	Parent Son/daughter	16(16)	37.25±25.58		
	Brother/Sister	16(16)	42.5±30.37		
	Cohabitant	4(4)	65.75±9.39		
	Friend	5(5)	60.8±21.39		
	Acquaintance	2(2)	12.5±4.94		
	Other relative	4(4)	67.75±35.36		
		10(10)	27.2±25.10		
Marital status	Married	64(63)	57.43±27.60	1 (0.39)	1.02 (0.38)
	Not Married	28(28)	36.5±29.93		
	Divorced	8(8)	49.5±26.87		
	Widower	1(1)	57±0		
Occupational status	Employee	46(46)	50.91±28.73	2.44 (0.05*)	0.78 (0.54)
	Freelancer	9(9)	59.55±29.47		
	Student	7(7)	10.71±15.20		
	Retired	22(22)	65.59±22.95		
	Unemployed	17(17)	44.41±27.20		
Psychophysical consequences of the stroke	Fear (presence)	81(81)	47.64±29.74	0.01 (0.91)	9.42 (<0.001***)
	Confusional states (presence)	61(61)	48.26±29.44	4.5 (0.03*)	4.4 (0.03*)
	Psycho-motor agitation (presence)	61(61)	50.32±30.54	0.61 (0.4)	6.37 (0.01**)
	Reduced state of consciousness	72(72)	49.30±29.65	0.07 (0.7)	4.92 (0.02*)
	Cognitive decline (presence)	54(54)	51.42±29.73	4.48 (0.03*)	6.03 (0.01**)
	Sleep disorders (presence)	67(67)	50.10±29.27	2.64 (0.10)	5.37 (0.02*)
	Decubitus injuries (presence)	43(43)	56.86±30.11	4.46 (0.03*)	8.04 (<0.001***)
	Degree of disability (severe)	47(47)	56.1±28.87	25.3 (<0.001***)	5.36 (<0.001***)
	Inadequacy (presence)	61(61)	49.91±29.33	6.21 (0.01*)	4.4 (0.03*)
	Arterial hypertension (presence)	65(65)	48±30.80	6.26 (0.01*)	0.84 (0.36)
Caregiver difficulties at the home level	Lack/Absence of disease info (a lot)	56(56)	52.56±29.57	2.81 (0.02*)	5.32 (<0.001***)
	Health care shortage/absence (a lot)	43(43)	50.93±31.72	2.61 (0.04*)	3.15 (0.01*)
	Lack/Absence of medication management info (a lot)	62(62)	49±30.42	2.89 (0.02*)	2.31 (0.06)
	Lack/Absence of psychological support (a lot)	69(69)	53.56±30.61	2.02 (0.09)	5.5 (<0.001***)
	Aid from local authorities (no)	78(78)	55.20±29.10	2.08 (0.15)	6.47 (0.01*)

Table 8. Metrics of classification performance.

	cm (TP FP ; FN TN)	Accuracy	Sensitivity	Specificity	Test AUC
Classification metrics	(9 0 ; 3 8)	85%	100%	73%	94%

cm: confusion matrix;
 FN: False Negatives;
 FP: False Positives;
 TN: True Negatives;
 TP: True Positives

**Figure 2.** AUC from the test ROC curve.

A substantial number of caregivers did not receive sufficient information or training to manage the care recipient's needs, leading to challenges during the initial caregiving phase. Additionally, our study reveals rather concerning data: the limited knowledge of local support entities for stroke patient care and the challenges related to transportation for post-discharge follow-up visits can lead caregivers to experience stress and depression, ultimately resulting in the use of antidepressants in 13% of cases. These findings emphasize the significance of implementing comprehensive training programs to provide caregivers with the essential skills and knowledge required for effective care and support.

This becomes especially crucial during the critical phases of stroke recovery. A longitudinal study further reveals that caregivers often encounter depressive symptoms and stress within the initial two weeks following a stroke event and again two weeks later (35). Therefore, the implementation of training strategies during this sensitive period of caregiving assistance is of paramount importance.

Furthermore, insights from a qualitative phenomenological study shed light on the integral role of caregivers during rehabilitation sessions. This involvement emerges as a fundamental factor in promoting patient empowerment within their care journey, concurrently alleviating caregiver stress levels (36). Equally noteworthy is the highlighted significance of social support networks through friends and family, as underscored by the works of Hanson et al. (37) and Bakas et al. (38). These cumulative findings contribute to a holistic understanding of the challenges and potential avenues for enhancing the well-being of both caregivers and stroke patients.

Furthermore, the lifestyle of care recipients before stroke and the psycho-physical consequences of stroke were explored in detail. Risk factors such as hypertension, smoking, sedentary behavior, and pre-existing medical conditions were highly prevalent among patients before experiencing a stroke, underscoring the necessity for targeted preventive interventions.

The assessment of caregivers' quality of life using the SF-36 questionnaire revealed strikingly low scores across various health domains. Caregivers reported poor physical functioning, bodily pain, and general health, indicating significant challenges in maintaining their own well-being while providing care.

The findings echo previous research that has shown the toll caregiving can take on caregivers' quality of life (28–30).

The perceived stress levels of caregivers were evaluated using the PSS-10 questionnaire. The results demonstrated considerable variability in stress scores, emphasizing the need for tailored interventions and support mechanisms to address caregivers' unique stressors and challenges.

In this study, a Machine Learning approach was also employed to predict the perceived stress levels of caregivers, using the SF-36 questionnaire only. The application of Machine Learning to health sciences is, of course, not new, but its widespread use to enhance the predictive power of questionnaires is relatively recent (39,40). The model has demonstrated itself as a rapid and accurate method for assessing both the quality of life and stress in this population. The obtained results highlighted a significant correlation between caregivers' quality of life levels and perceived stress, underscoring the importance of considering both aspects in the overall assessment of caregiver well-being. This methodology holds the potential to be applied in clinical and research settings to early identify high-risk caregivers for stress, facilitating the implementation of targeted interventions aimed at improving their quality of life and reducing the stress burden associated with home caregiving activities. It is important to emphasize that, while being a valuable tool, the Machine Learning approach does not replace the competence and empathy of professionals in assessing and assisting caregivers. However, the combination of clinical expertise and technological tools can represent a crucial synergy to optimize care and promote the well-being of this valuable category of caregivers. To prevent stress and burnout, timely psychological support should also be offered. A well-prepared and emotionally supported caregiver will undoubtedly be more capable of effectively utilizing available community services and taking better care of the patient. Indeed, the future of healthcare must involve the enhancement of the community and its resources, with greater involvement of the family unit, which should be more considered and assisted.

The findings of our study depict a concerning scenario and imply a reflection: analyzing predictive

factors of suicide risk among caregivers, an aspect to be explored through future prospective longitudinal studies that have not yet been addressed in the literature.

In conclusion, this study provides valuable insights into the experiences of caregivers of stroke patients, highlighting the need for improved education, training, and support for caregivers.

The limitations of the study include the decision to conduct an online study, which may have excluded caregivers with limited computer literacy; therefore, the sample may not be representative of the entire caregiver population, with potential selection biases inherent in the study design choice.

In the management of stroke and its impact on patients' lives, caregivers play a fundamental role. Caregivers are those who provide care and support to stroke-affected patients, often assuming significant responsibility in delivering daily care and assistance. They face emotional, physical, and financial challenges, as stroke can bring about significant lifestyle changes for the patient and require long-term commitment to the rehabilitation process. The quality of caregivers' lives can be influenced by various factors, including the level of stress related to caregiving responsibilities, the balance between work and caregiving, and the received social support. Understanding caregivers' experiences and well-being is crucial for developing targeted interventions to support them in their caregiving role. In this context, our study aims to examine new perspectives on the relationship between caregivers' quality of life and the stress associated with caring for stroke patients. These findings could inform the development of specific support programs for caregivers, aimed at improving their quality of life and mitigating the impact of caregiving-related stress. Additionally, the importance of developing strategies to accompany caregivers on a training and preparation journey that aligns well with the workload they will face, especially in the early stages of caregiving, has emerged.

The Machine Learning approach used to predict perceived stress levels of caregivers using the SF-36 questionnaire as an independent variable has also allowed us to quickly and accurately estimate caregivers' quality of life and stress levels, saving time and resources in the evaluation process. Furthermore, this approach highlights the correlation between quality of life levels and perceived stress among caregivers.

In conclusion, our study contributes to the understanding that stroke is a condition that involves not only the affected patient but also their caregivers. The focus on caregivers' health and well-being is crucial to promoting better stroke management and improving the quality of life for those providing care to those affected by this catastrophic event.

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Authors Contribution: Conceptualization: LC, RL, PL and MD; methodology: LC, RL, PL, MD, and AL; analysis: LC; investigation: LC, RL, PL, MD, AL, AF, GA, MC, CTN, EV, IR; writing original draft: LC; supervision: GA, MC, CTN, EV, IR, and GDN. All authors have read and agreed to the published version of the manuscript.

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