

# Informal caregivers of patients affected by stroke: strategies for reduction overload

## Cuidadores informais de pacientes acometidos pelo acidente vascular cerebral: estratégias para a redução da sobrecarga

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### Abstract

**Introduction:** The act of daily care for patients affected by stroke is challenging and requires pluralistic knowledge, ranging from techniques related to health care, to psychological issues. Generally, these caregivers report several complaints, physical, mental and social problems in the act of caring for this patient. **Objective:** Identify possible strategies described in the literature that seek to reduce the physical, mental or social overload of informal caregivers of patients affected by stroke. **Method:** This is an integrative literature review, carried out between September 2022 and January 2023, with the following guiding question: What Can strategies described in the literature reduce the burden of informal caregivers of patients affected by stroke? The search was carried out in PubMed, SciELO and VHL databases. **Results:** 533 studies were found during the search, of which eight studies were selected to discuss the results. The summed total sample of informal caregivers was 687, with a mean age of 50.8 years; being 502 (73.07%) women and 185 (26.92%) men. The main strategies found in the literature were: health education in different ways (psychoeducation, guidance via telephone call, verbal guidance) and progressive muscle relaxation. **Conclusion:** There are strategies that aim to reduce the physical, mental and social burden of informal caregivers of patients affected by stroke. However, further studies are needed to address these strategies, especially studies that report in more detail the interventions performed.

**Keywords:** caring charge, health strategies, caregiver burden

### Resumo

**Introdução:** O ato de cuidados diários de pacientes acometidos pelo Acidente Vascular Cerebral é desafiador e requer conhecimentos pluralistas, que vão desde técnicas relacionadas à assistência em saúde, até questões psicológicas. Geralmente, estes cuidadores relatam diversas queixas, problemas físicos, mentais e sociais diante do ato de cuidar deste paciente. **Objetivo:** Identificar possíveis estratégias descritas na literatura que buscam diminuir a sobrecarga física, mental ou social de cuidadores informais de pacientes acometidos pelo Acidente Vascular Cerebral. **Metodologia:** Trata-se de uma revisão integrativa de literatura, realizada entre os meses de setembro de 2022 a janeiro de 2023, com a seguinte questão norteadora: Quais estratégias descritas na literatura podem diminuir a sobrecarga de cuidadores informais de pacientes acometidos pelo acidente vascular cerebral? A busca foi realizada nas bases de dados PubMed, SciELO e BVS Saúde. **Resultados:** Foram encontrados 533 estudos durante a busca, destes, oito estudos foram selecionados para a discussão dos resultados. A amostra total somada de cuidadores informais foi de 687, com média de idade de 50,8 anos; sendo 502 (73,07%) mulheres e 185 (26,92%) homens. As principais estratégias encontradas na literatura foram: educação em saúde de diferentes formas (psicoeducação, orientações via telefonema, orientações verbais) e o relaxamento muscular progressivo. **Conclusão:** Existem estratégias que visam reduzir a sobrecarga física, mental e social de cuidadores informais de pacientes acometidos pelo acidente vascular cerebral. Entretanto, são necessários mais estudos que abordem outras estratégias, principalmente estudos que relatem de forma mais detalhada as intervenções realizadas.

**Palavras-chave:** carga de cuidar, estratégias de saúde, fardo do cuidador

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## Introduction

Cerebrovascular accident (Stroke) is one of the leading causes of disability and mortality in the world, and can be defined as the sudden loss of neurological function caused by an interruption or reduction of blood flow to the brain that exceeds 24 hours<sup>1</sup>. According to World Stroke Organization data<sup>2</sup> almost 6.6 million people die from the condition and its consequences every year. After the stroke, changes occur in the patient's life, mainly because it involves a prolonged recovery period, often causing physical disability and functional deficit for several tasks and daily activities<sup>3</sup>. Among these, the most common consequences identified are motor, cognitive, and sensory impairments, leading to limitations in movement or mobility for walking and balance. In addition to affecting vision, swallowing, and communication functions<sup>4</sup>. Other negative outcomes that stroke patients may have are the difficulties related to returning to work, return to activities of daily living (bathing, dressing, eating); as well as problems to drive themselves to some place, to do leisure programs and related to the practice of physical activity<sup>3</sup>.

In face of this new scenario, most of the times it becomes essential the presence of a caregiver to help in the daily tasks of these patients. These caregivers can be defined as unpaid people to perform the act of caring for another person (informal caregiver - IC): companions or spouses, family members or family caregiver, friends or other close people who provide physical, transportation, or emotional help to the patient. Formal caregiver: person outside the family, who is paid for the task, and may or may not have academic training or adequate knowledge to perform the care<sup>5</sup>. And finally, it is possible to mention family caregivers who stay for shorter periods of time, either because of work, or because they are able to divide the tasks, counting on

the support of a family member or another person to perform the patient's care<sup>6</sup>.

In neurological pathologies, as in the case of stroke, the experience of caregiving may generate an overload or burden as a response to physical, emotional, psychological and social stressors, which affects the biological, psychological, sociological, ethnic, cultural and religious aspects of caregivers' lives<sup>7</sup>. Overload is understood as the accumulation of work in the act of caring for a dependent person, where the caregiver suffers negative changes in his/her physical, emotional and social health and increased insecurity; as well as the inability to separate moments of work and leisure.<sup>8</sup> Depending on the factors affected, ICs are at significant risk for mental health problems and physical disorders that arise as a result of a psychological disorder, such as insomnia and appetite problems. Feelings of guilt and incompetence in providing adequate care are also reported, as well as financial difficulties, where these caregivers may have to abandon their careers, reduce their workload, or even quit their jobs, resulting in a loss of income<sup>9</sup>.

Specifically, the Informed Consent of stroke patients report that they are not always prepared to assume the responsibilities of continuous care of their family member<sup>10</sup>. The period after discharge from the hospital is described by them as a challenging and stressful time, since most of the time they report not having previous experience in caregiving or the lack of understanding of how they should meet the demands of the family member's new reality<sup>11</sup>. When the stroke patient is discharged from the hospital and goes home, many times, the family members who become the caregivers of these patients lose all the emotional, social and practical support they had inside the hospital<sup>12</sup>. As well as, there is a decrease or lack of guidance related to the care of these patients, which can sometimes become irreversible difficulties.<sup>13</sup>



Magagnin e Heidemann<sup>12</sup> report that caregivers show confidence in the multiprofessional team in the hospital environment during the rehabilitation of stroke patients. However, these caregivers have difficulties and lacks in the process of caring after discharge. Therefore, caregivers who do not have adequate support and social support may have their health affected by the overload they are receiving; they may manifest physical symptoms, depression, stress, leading to a worsening in their quality of life<sup>13</sup>. Silva and co-workers<sup>8</sup>, concluded that 98.2% of the ICs did not know the causes of stroke, symptoms, or what to do to rescue a victim, and had not been taught how to care for a stroke patient in the home environment. Camak<sup>10</sup> described that the challenges expressed by caregivers include feelings of loneliness and isolation, exhaustion, difficulty sleeping, lack of information about the patient's prognosis, and lack of information about the care needs of stroke patients. Given this scenario, it is necessary that preventive strategies be used to reduce the risks related to the overload that the act of caring for the patient can cause<sup>14,15</sup>.

The literature on the theme already shows that ICs have difficulties, burdens, overloads and complaints related to the act of caring for stroke patients. Therefore, it is necessary to discuss the possible strategies and solutions described in the literature that seek to reduce the negative impacts that the act of caring can cause in the IC of stroke patients. Thus, the aim of this study is to identify possible strategies described in the literature that seek to reduce the physical, mental, or social overload of informal caregivers of stroke patients.

## Materials and Methods

### Study Area

This is an integrative literature review, conducted between September 2022 and January 2023, built through six recommended steps. The first step was

performed by identifying the topic and the guiding question of the study; the second step refers to the establishment of inclusion and exclusion criteria for the study. The third step was the search and identification of possibly selectable studies. The fourth and fifth steps dealt with the categorization and analysis of the data obtained; and the last step was for the presentation of the results.

### Clinical question and descriptors

The guiding question adopted for this study was: Which strategies described in the literature can reduce the burden of informal caregivers of stroke patients? The following keywords were used to select the articles: Informal caregivers, stroke, stroke, caregiver burden, caregiver burnout; The search was conducted on the platforms National Library of Medicine (PubMed), Scientific Electronic Library Online (SciELO) e BVS Saúde.

### Criteria for Inclusion and Exclusion

The studies included in this review met the following inclusion criteria: abstract available in the described databases; publication language Portuguese, English or Spanish; publication period between the years 2013 and 2022; clinical trials or randomized clinical trials, as well as pertinent theme about the strategies that aim to reduce the burden of informal caregivers of patients with clinical diagnosis of stroke. Review studies and studies that did not explore the established theme were excluded from the search.

### Collecting and Analyzing Data

The search, selection of studies and data extraction was performed by three examiners considering their insertion in the databases until December 2022. The data on the studies were synthesized in the form of a table containing: title, authors, sample,



objective, design, and results with the purpose of providing comparative analysis and descriptive synthesis.

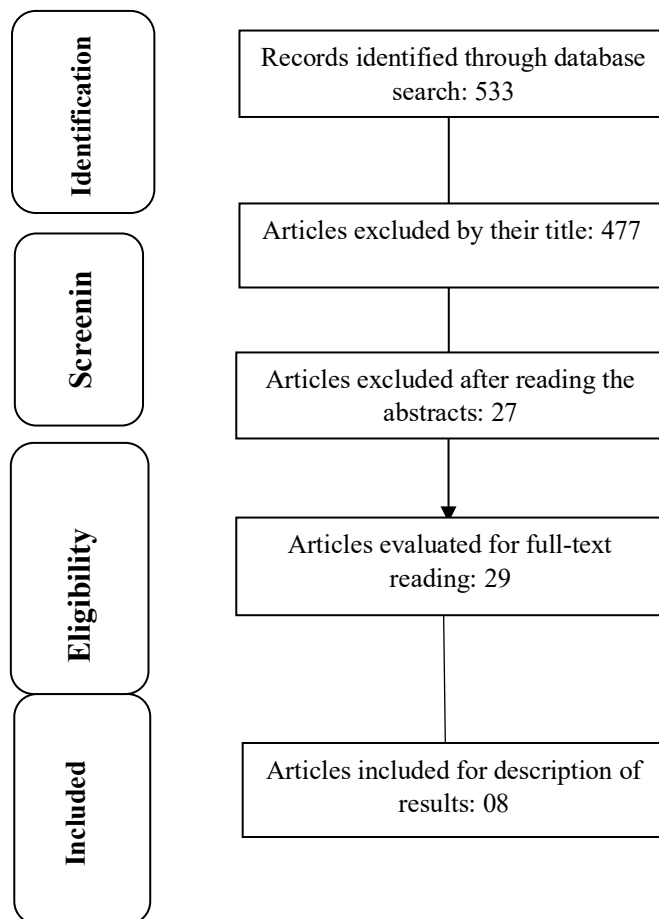
## Results

From the digital search, 533 articles were located, distributed in the databases as follows: BVS – 11; PubMed – 492 e SciELO – 30. Of this total, 525 articles that did not meet the previously established

inclusion criteria were discarded, leaving eight studies for discussion of the results.

Figure 1 shows the number of studies excluded at each stage. The main reasons for exclusion of studies were: duplicate studies, review or unpublished studies, articles that did not talk exclusively about patients diagnosed with stroke, studies that cited burden of the patient and not of the caregiver, and studies that did not discuss the theme of burden in caregivers of patients affected by stroke.

Figure 1. Flowchart of the literature search for evidence on the researched theme.



Source: elaborated by the authors.

Regarding the source of the studies, they were published in the following journals: Acta Neurologica Belgica; BMC Health Services Research; BMJ Open; Clinical Gerontologist; Health and Social

Care in the community; International Journal of Nursing Studies; Japan Journal of Nursing Science e Medicine.

**Table 1.** Information from the studies included in the review

Authors and publication year	Sample	Purpose	Delineation	Results
Ho Yu Cheng, Sek Ying Chair, Janita Pak Chun Chau, 2018.	128 caregivers (96 women and 32 men). (IG=64) (CG=64) caregivers. Mean age (49.1 ± 12.5 years).	To evaluate the effectiveness of an inner strength-oriented psychoeducational program on caregiving competence, problem-solving skills, caregiver depressive symptoms, caregiving burden and resources (family functioning, social support), and physical health (such as caregiving-related injuries).	Longitudinal study (2012 to 2014). Initially conducted in medical wards of hospitals. Caregivers completed questionnaires related to caregiving and burden before, during, and one and three months after the intervention. The CG received usual care, while the IG received an additional 26-week psychoeducational program geared toward inner strength (two pre-discharge structured individual face-to-face education sessions about stroke and its associated caregiving skills and six bi-weekly post-discharge telephone sessions) and problem-solving-based coping skills training sessions).	The IG demonstrated significant improvements throughout the study ( $p < 0.01$ ) in terms of caregiving competence, problem-solving coping skills, and satisfaction with social support, and a lower level of burden three months after the intervention when compared to the CG.
Yilmaz <i>et al.</i> , 2018	44 caregivers (37 women and 7 men) (IG=23) and (CG=21). Mean age: 50.29 years.	To investigate the effect of progressive muscle relaxation on burden and level of depression among caregivers of elderly people with stroke.	Study conducted at home care unit in Turkey. The GI caregivers practiced PMR exercises after receiving verbal training on how to practice them. The sessions lasted 28 min, 3 times a week for 8 weeks. The CG had no intervention. The caregivers were given the <i>Zarit Caregiver Burden Scale</i> and <i>Beck Depression Scale (BDS)</i> .	There was a statistically significant difference ( $p < 0.05$ ) in the mean scores of the caregivers of GI when compared to CG before and after the practice of RPM.
Day <i>et al.</i> , 2020.	48 caregivers (42 women and 6 men) (IG=24) and (CG=24). The mean age was 73.0 ± 10.3 in GI and 74.3 ± 8.5 in CG.	To evaluate the effect of nursing intervention in home care on the burden of family caregivers of elderly stroke survivors	The IG received three home visits by nurses in 1 month after hospital discharge for orientation about the disease and patient care. The CG relied on the care network they had access to. During the home visits, verbal orientations with a problematizing educational approach were performed. The nurses started with the family's demands regarding their needs and performed practical demonstrations of care activities, according to the resources available in	The intervention had a positive effect on family caregiving burden in the domain 'Isolation' ( $p=0.037$ ) and in the domain emotional involvement ( $p=0.003$ ) over time in GI.



Authors and publication year	Sample	Purpose	Delineation	Results
			the homes. The Caregiver Burden Scale was applied to evaluate the outcome of overload at 1 week, 60 days, and 1 year after hospital discharge.	
Fu <i>et al.</i> , 2020	68 caregivers (32 women and 36 men) (IG=34) and (CG =34). Mean age in GI: 68.56 ± 5.90 and 67.00 ± 4.42 in CG.	To verify the effectiveness and feasibility of a nine-week intervention on burden, quality of life in informal caregivers of stroke survivors.	The intervention program consisted of 9 weeks of individual interventions (for 45 minutes) with the participants. The intervention site was in the stroke patient's home. The IG received a nine-week health education routine. Questionnaires were applied at the beginning and one week after the intervention, where the caregivers' quality of life, burden, and the benefits achieved by the intervention were verified.	It observed statistically significant difference ( $p < .005$ ) on caregiver quality of life, finding of benefits and caregiver burden of stroke survivors in both groups.
Mehmet Akif Guler, Belgin Erhan, Ebru Yilmaz Yalcinka ya, 2020.	63 caregivers (46 women and 17 men) divided into: GI =31 and GII = 32). The age in GI was 42.61±13.43 and in GII was 42.63±13.85.	Evaluate the caregivers' burden during the inpatient rehabilitation of the hospitalized patient and compare the associations of robot-assisted gait training and conventional therapy with the level of caregiver burden.	Group I received robot-assisted gait training for 30 minutes, associated with conventional therapy for 1 hour a day for 15 days. Group II underwent the same interventions in the reverse order (conventional therapy followed by robot-assisted gait training). The following were applied: <i>Caregiver burden inventory</i> ; <i>Beck (depression)</i> ; <i>Beck (hopelessness scale)</i> .	During inpatient rehabilitation, both robot-assisted gait training and conventional therapy increased caregiver burden ( $p= 0.000$ ) in both groups.
Farahani <i>et. al.</i> , 2021	116 caregivers (83 women and 33 men), with a mean age of 43.98 in (GI= 58) (N=58) and 43.41 in (CG=58).	To evaluate the effect of a home-based program on caregiver burden in stroke patients.	After the caregivers were divided into IG and CG, the sociodemographic and <i>Caregiver Burden Inventory (CBI)</i> , of 24 items. The CG caregivers received the instructions on routine patient care and education while still in the hospital. The caregivers from GI, on the other hand, had eight educational intervention sessions, the first two of which were held while the patient was still in the hospital and the other six at the patient's	There was a significant difference between the two groups regarding caregiver burden scores after the intervention period ( $p < 0.001$ ), where the control group had a higher burden score.



Authors and publication year	Sample	Purpose	Delineation	Results
			home within 2 weeks. Each session lasted 45 to 60 minutes. Both groups answered the CBI again 2 weeks after hospital discharge.	
Wang <i>et. al.</i> , 2021.	110 caregivers (84 women and 26 men) distributed in intervention (IG) (N=55) and control (CG) groups (N=55). Mean age 47.3 years±10.4 years in GI and 47.6 years±10.2 years in CG.	To find out the effect of muscle education and relaxation (EMR) program on anxiety, depression and caregiver burden among caregivers of acute stroke survivors.	The following scales were applied to the caregivers of patients who were hospitalized: <i>Hospital Anxiety and Depression Scale (HADS)</i> and the <i>Zarit Caregiver Burden Scale</i> . These were assessed at the time of the patient's discharge from the hospital, then at month 3, 6 and 12 after discharge. Caregivers in the CG received common rehabilitation advice and those in the IG were asked to go twice a month to receive health education for 12 months and progressive muscle relaxation. Each session lasted 90 minutes and included 3 procedures: a 30-minute health education, a 30-minute muscle relaxation demonstration by the investigator, and a 30-minute muscle relaxation practice.	Caregivers in both groups showed reduced caregiver burden indirectly through decreased anxiety and depression ( $p < 0.005$ ).
Elsheikh <i>et. al.</i> , 2022.	110 caregivers (82 women and 28 men), divided into intervention (IG) (n=55) and control (CG) groups (n=55). Mean age 35 years.	To evaluate the effectiveness of a personalized multidimensional intervention in reducing the caregiver burden of stroke survivors.	The IG underwent an intervention developed by the researchers after an interview conducted with the caregivers. Each caregiver received the intervention according to their complaints. It lasted 6 months, with 3 home visits of 120 min, 6 phone calls of 40 min, and 1 support session of 90 min. The CG received an instructional booklet with information about stroke and its care. The instructions were passed on through a home visit. Sociodemographic questionnaires were applied to both groups, <i>Zarit Birden Interview</i> e	The intervention had no significant effect on outcomes between or within groups over time in terms of burden ( $p \geq 0.05$ ). However, the group and time interaction had positive main effects on caregivers' QL (psychological and social domains).



Authors and publication year	Sample	Purpose	Delineation	Results
			WHOQOL-BREF in three collection times that were divided into T0 (before the intervention), T1 (3 months) and T2 (6 months).	

Source: elaborated by the authors, 2023.

IG: Intervention Group; GC: Control Group; G1: Group 1; G2: Group 2; PMR: Progressive Muscle Relaxation

### *Characteristics of the included trials*

The studies evaluated were published between 2013 and 2022, considering the next ten-year period. The total summed sample of informal caregivers in the eight studies was 687, with a mean age of 50.8 years. As for gender, the ICs were 502 (73.07%) women and 185 (26.92%) men.

In five studies, the reduction of burden was analyzed with health education activities, which included: face-to-face verbal guidance and by phone call; guidance on the best way to care for the patient, teaching about stroke, about medications, about treatments, and possible exercises for the patients.

In two studies the progressive muscle relaxation technique was analyzed, with the purpose of reducing the muscle tension present in the caregivers, with verbal and practical training on how to perform it.

In one study, the intervention with conventional therapy and gait training in stroke patients was analyzed during the hospital rehabilitation period, comparing the burden levels of their caregivers to these interventions.

### **Discussion**

The current review sought to summarize the possible guiding strategies to reduce issues related to the physical, mental or social burden of IC of stroke patients. It was observed that strategies such as health education in different ways

(psychoeducation, guidance by telephone, verbal guidance) and progressive muscle relaxation are described in some studies as possibilities to reduce this condition. Among these, the strategy most reported in the literature to achieve positive effects in the IC overload of patients affected by stroke was in relation to health education and its related methods.

Cheng and co-workers<sup>16</sup> concluded that a psychoeducational program geared toward the caregivers' inner strength, with phone-based coping skills training and education about stroke, had positive results regarding caregiving competence and caregiver social support. It also decreased the physical burden on informal caregivers. In another study included for discussion of the topic in this review, a nine-week program was conducted with health education for caregivers, providing information on disease management, guidance on medications, diet, and family rehabilitation exercises. The authors reported that it effectively improved the quality of life, reduced the burden, and awakened the discovery of benefits in caregiving, which means generating in the caregiver positive psychological feelings about the role of caring<sup>17</sup>.

Day and collaborators, 2020 brought that an intervention of verbal orientations of educational approach with demonstrations before the negative demands presented by the family before the care, had positive effects on the burden of care. Elsheikh and collaborators<sup>18</sup> concluded that educational actions combined with professional support and training of caregivers is an adequate





proposal for a job with better quality of life and less burden. In the study by Farahani e collaborators<sup>19</sup> showed that health educations related to the etiology, the signs and symptoms of the disease, the types of treatments, the importance of patient care, and other therapies employed showed a decrease in burden scores when compared to a control group that did not receive the same interventions.

The literature reports in some studies the importance and potential of the act of health education as a form of support for people in patient care<sup>20</sup>. In the study by Bernal et al.<sup>21</sup> with caregivers of people with chronic diseases, it was observed that three educational sessions on emotional support, adaptation to the new role, and training for the caregiver on home care skills contributed positively to the reduction of the caregivers' burden, and to the improvement of issues related to depression and anxiety. In another study with emotional support and health education for caregivers of patients with Alzheimer's disease, positive results were obtained in the improvement of cognitive performance, as well as a decrease in stress and anxiety symptoms of these caregivers<sup>22</sup>.

Therefore, it is observed the positive role that health education can have in caregivers of patients with several pathologies. Specifically in the case of stroke, the literature already shows us some benefits of this intervention. It is necessary that further studies on the theme explore this content and use other strategies to perform health education in ICs of patients affected by stroke. As well as, it is necessary that studies report in more detail how health education should be performed for these caregivers, considering the beginning of the patient's treatment process, in the hospital, and the continuity of this follow-up outside the hospital. Moreover, as simple as a health education intervention may seem, it is also necessary to consider that health professionals must be able to perform this task, with proper training since graduation,

with the insertion of courses and training aiming to prepare the future professional for the task, with health education being a routine strategy in the search for a more integral and humanized care<sup>23</sup>. It is also important that this health education network for IC happens over time and continuously, offering them the necessary information throughout the progression of the disease<sup>24</sup>.

Few studies have attempted to assess caregiver burden during the period of hospitalization of stroke patients. In the current revision, Guler and co-workers 2020 performed gait training with the use of orthoses for the lower limbs combined with conventional therapy in stroke patients in order to evaluate the short-term impact of rehabilitation during the hospital period on the caregiver's burden. The results showed that the burden index of these caregivers increased; however, the authors discuss that this increase was not directly and only related to the therapies performed, but because it is a new period of anguish, adaptations, and uncertainty about the future outcome in the lives of patients and caregivers, being this the period that will demand more from these caregivers. Backx and co-workers<sup>25</sup> also investigated the burden of caregivers during the hospital rehabilitation period of patients with spinal cord injury and concluded that during the hospitalization period there is a high burden and low quality of life of the analyzed caregivers. However, during the initial phase at home, a significant improvement in burden and quality of life was found, which may be related to the improvement of the patients' physical abilities and to the caregiver's adaptation to the new reality and routine.

It is important to consider that rehabilitation, gait and balance training are considered to be first-order coping and recovery strategies for stroke patients. Lima and collaborators<sup>26</sup> brought in their review the importance of physiotherapy in the recovery of post-stroke patients. It was observed that these patients present low



physical conditioning and reduced muscle strength; and the physiotherapeutic intervention improved these deficits. Therefore, it is expected that as a consequence of the improvements in relation to the patient's functional performance, the patient will be less physically limited and will depend less and less on a caregiver, decreasing the levels of burden.<sup>27</sup> Therefore, it becomes extremely necessary that future studies investigate the relationship between the issue of physical rehabilitation of the acute and chronic stroke patient with the levels of caregiver burden in the hospital environment, at home, and in physical rehabilitation services.

Rodrigues and co-workers<sup>28</sup> provided caregivers with orientation and training during the hospital period for dependent patients with no specific pathologies, followed by follow-up care at home after discharge. For control, they compared it to another group that did not get this follow-up. Significant results were observed between the groups for cognitive, emotional, relational, and psychomotor skills for the "Informal Caregiver Skills Assessment Questionnaire". (COPER-14). Therefore, the authors conclude that ICs benefit from educational programs and have greater potential for providing care for dependent patients after hospital discharge.

Another strategy to decrease the IC overload levels found in the search was the progressive muscle relaxation technique (MRT). This practice consists of directing attention to a certain muscle group, contracting it, holding the contraction for a period of time, and then relaxing it. The process is repeated on different muscle groups with the purpose of experiencing the feeling of relaxation in the whole body, with the goal of reducing muscle tension, which may be present in caregivers<sup>29</sup>. In the included study for discussion, Yilmaz and co-workers<sup>30</sup> performed exercises of MRT and the anxiety and depression scores of the ICs of stroke patients showed a reduction

after the sessions. Wang and co-workers<sup>31</sup> held MRT associated with health education and concluded that caregivers of stroke patients had a reduced burden of care by reducing anxiety and depression. In the literature search, no other studies were found that used the MRT technique in caregivers of patients with some other type of pathology for comparison purposes. Therefore, further research is needed to investigate the effects of the technique, so that it can be implemented and disseminated in the search for the physical well-being of the ICs of stroke patients.

It is described in the literature that some physical exercise modalities (weight training, walking, running) and psychotherapeutic techniques are beneficial for caregivers<sup>32-34</sup>. Loi and co-workers<sup>35</sup> investigated physical activity and psychological status in caregivers and concluded that these interventions improved their stress, depression, and burden. Batista and co-workers<sup>36</sup> conducted a program of resistance exercise with mothers of children and adolescents with cerebral palsy and concluded that the regular practice of these exercises had a positive impact on the health-related quality of life, on the perception of burden, and reduced the intensity of depressive symptoms of the participants. Regarding the issue of stroke, no studies were found that address these strategies for IC of patients affected by the condition. Future investigations that address physical activity and psychotherapy are necessary in order to promote quality of life and reduce the burden of IC in stroke patients.

Another important characteristic in the analyzed studies that should be elucidated is that the great majority (73.07%) of the ICs were female. Garcia and co-workers<sup>6</sup> brought in their study that 85.5% of the number of caregivers of dementia patients are female and this may be related to the fact that women, historically, have their social role determined as caregivers and suffer greater



impact than men for assuming this role<sup>37</sup>. Therefore, it is necessary that new studies consider the issue of feminization in caregiving, as well as address possible issues related to the difference between genders in the act of caring; so that in the future public policies and directions are thought considering the specificities of the profile of these caregivers.

## Conclusion

There are strategies described in the literature that seek to reduce the IC overload of patients who have suffered a stroke. Among the strategies observed, one can report: health education in different forms

and muscle relaxation techniques. However, more studies are needed that delve into these strategies, especially studies that report in more detail how these interventions should be performed. It is also emphasized the need to study other strategies that can help these caregivers, such as the issue of rehabilitation improving the patient's physical and functional capacity, and consequently decreasing the IC's burden levels. Besides the need to study other strategies that were not addressed as possibilities for these caregivers, such as the implementation of physical exercises, psychotherapeutic monitoring, and support from health professionals over time..

## Bibliographical References

1. De T, Botelho S, Diniz C, Neto M, Longo Correia De Araújo F, Campos De Assis S. Epidemiologia do acidente vascular cerebral no Brasil. *Temas em Saúde*. 2016;16:361-377.
2. World Stroke Organization. *World Stroke Organization Annual Report 2021*.; 2021. doi:[https://www.world-stroke.org/assets/downloads/Annual\\_Report\\_2021\\_online\\_latest.pdf](https://www.world-stroke.org/assets/downloads/Annual_Report_2021_online_latest.pdf)
3. Cameron JI, O'Connell C, Foley N, et al. Canadian Stroke Best Practice Recommendations: Managing transitions of care following Stroke, Guidelines Update 2016. *International Journal of Stroke*. 2016;11(7):807-822. doi:10.1177/1747493016660102
4. Fryer CE, Luker JA, McDonnell MN, Hillier SL. Self management programmes for quality of life in people with stroke. *Cochrane Database of Systematic Reviews*. 2016;2016(8). doi:10.1002/14651858.CD010442.pub2
5. Pindus DM, Mullis R, Lim L, et al. Stroke survivors' and informal caregivers' experiences of primary care and community healthcare services – A systematic review and meta-ethnography. *PLoS One*. 2018;13(2). doi:10.1371/journal.pone.0192533
6. Cuevas-Martinez KI, Gutiérrez-Valverde JM. Caracterización de los cuidadores informales de adultos mayores en situación de pandemia por COVID-19 en Tamaulipas, México. *SANUS*. 2022;7:e265. doi:10.36789/revsanus.vi1.265
7. Kunkle R, Chaperon C, Berger AM. Formal Caregiver Burden in Nursing Homes: An Integrative Review. *West J Nurs Res*. 2021;43(9):877-893. doi:10.1177/0193945920979691
8. da Silva IFG, da Silva Neves CF, Vilela ACG, Bastos LMD, Henriques MILS. Living and Caring After a Stroke. *Revista de Enfermagem Referencia*. 2016;4(8):103-111. doi:10.12707/RIV15047
9. Ransmayr G, Hermann P, Sallinger K, et al. Caregiving and caregiver burden in dementia home care: Results from the prospective dementia registry (PRODEM) of the Austrian Alzheimer Society. *Journal of Alzheimer's Disease*. 2018;63(1):103-114. doi:10.3233/JAD-170657
10. Camak DJ. Addressing the burden of stroke caregivers: A literature review. *J Clin Nurs*. 2015;24(17-18):2376-2382. doi:10.1111/jocn.12884
11. da Costa SRD, de Castro EAB. Self-care in family caregiver of dependent adults or elderly persons after hospital discharge. *Rev Bras Enferm*. 2014;67(6):979-986. doi:10.1590/0034-7167.2014670617



12. Magagnin AB, Heidemann ITSB. Empowerment of family caregiver in front of stroke in hospital environment. *Rev Bras Enferm.* 2020;73(4):e20190165. doi:10.1590/0034-7167-2019-0165
13. da Silva JK, Boery RNSDO. Family caregivers of stroke survivors: Burden and related factors. *Ciencia y Enfermeria.* 2021;27(11):1-10. doi:10.29393/ce27-11cfjr20011
14. Maria de Castro L, Neri de Souza D. *Programa de Intervenção Psicossocial Aos Cuidadores Informais Familiares: O Cuidar e o Autocuidado.*; 2016. doi:https://doi.org/10.25755/int.11819
15. Jenifer Milena Zabala-Gualtero, Miguel Oswaldo Cadena-Sanabria. Enfermedad de Alzheimer y Síndrome de Carga del Cuidador la importancia de cuidar al cuidador. *Médicas UIS.* Published online 2018. doi:https://doi.org/10.18273/revmed.v31n1-2018001
16. Cheng HY, Chair SY, Chau JPC. Effectiveness of a strength-oriented psychoeducation on caregiving competence, problem-solving abilities, psychosocial outcomes and physical health among family caregiver of stroke survivors: A randomised controlled trial. *Int J Nurs Stud.* 2018;87:84-93. doi:10.1016/j.ijnurstu.2018.07.005
17. Fu B, Mei Y, lin B, et al. Effects of A Benefit-Finding Intervention in Stroke Caregivers in Communities. *Clin Gerontol.* 2022;45(5):1317-1329. doi:10.1080/07317115.2020.1765062
18. Elsheikh MA, Moriyama M, Rahman MM, et al. Effect of a tailored multidimensional intervention on the care burden among family caregivers of stroke survivors: A randomised controlled trial. *BMJ Open.* 2022;12(2). doi:10.1136/bmjopen-2021-049741
19. Ashghali Farahani M, Najafi Ghezalje T, Haghani S, Alazmani-Noodeh F. The effect of a supportive home care program on caregiver burden with stroke patients in Iran: an experimental study. *BMC Health Serv Res.* 2021;21(1). doi:10.1186/s12913-021-06340-4
20. Roosby Gallardo Solarte, Vilma Ortiz Nievas. Impacto de la intervención pedagógica en la competencia de cuidado. *Revista Ciencias de la Salud.* 2021;19:1-15. doi:https://doi.org/10.12804/revistas.urosario.edu.co/revsalud/a.10282
21. Hernández Bernal N, Barragán Becerra J, Moreno Mojica C. Intervención de enfermería para el bienestar de cuidadores de personas en cuidado domiciliario. *Revista Cuidarte.* 2018;9(1):2045. doi:10.15649/cuidarte.v9i1.479
22. de Souza Caparrol AJ, Martins G, Barbosa GC, Gratão ACM. Effects of a psychoeducational intervention focusing on cognitive training in caregivers of older adults with Alzheimer's disease. *Brazilian Journal of Occupational Therapy.* 2021;29. doi:10.1590/2526-8910.ctoAO2181
23. Aco B, Cba R, Mif A, Rb B, Sr R. *Perception of the Primary Care Multiprofessional Team on Health Education.* Vol 72.; 2019.
24. Michel Miranda do Vale J, Corrêa Marques Neto A, Maria Silva dos Santos L, Elizabeth de Santana M. *Educação Em Saúde Ao Familiar Cuidador de Adoecidos Em Cuidados Paliativos Oncológicos Domiciliares.* Vol 10.; 2019. doi:https://doi.org/10.21675/2357-707X.2019.v10.n2.1684
25. Backx APM, Spooren AIF, Bongers-Janssen HMH, Bouwsema H. Quality of life, burden and satisfaction with care in caregivers of patients with a spinal cord injury during and after rehabilitation. *Spinal Cord.* 2018;56(9):890-899. doi:10.1038/s41393-018-0098-7
26. Lima JB, Máxima N, Conceição P, De Y, Tapparelli A. *A Fisioterapia Motora No Processo de Reabilitação Do Acidente Vascular Encefálico.*; 2021.
27. Lopes CC, Oliveira GA de, Stigger F de S, Lemos AT de. Associação entre a ocorrência de dor e sobrecarga em cuidadores principais e o nível de independência de idosos nas atividades de vida diária: estudo transversal. *Cad Saude Colet.* 2020;28(1):98-106. doi:10.1590/1414-462x202028010184
28. Rodrigues TFC da S, Cardoso LCB, Rêgo A da S, Silva ES, Elias M de F de AL, Radovanovic CAT. Educational intervention to increase the skill of informal caregivers: A



- quasi-experimental pilot study. *Texto e Contexto Enfermagem*. 2021;30. doi:10.1590/1980-265X-TCE-2020-0152
29. Silveira E de A, Batista K de M, Grazziano E da S, Bringuete ME de O, Lima E de FA. Effect of progressive muscle relaxation on stress and workplace well-being of hospital nurses. *Enfermeria Global*. 2020;19(2):485-493. doi:10.6018/eglobal.396621
  30. Yilmaz CK, Aşiret GD, Çetinkaya F, Oludağ G, Kapucu S. Effect of progressive muscle relaxation on the caregiver burden and level of depression among caregivers of older patients with a stroke: A randomized controlled trial. *Japan Journal of Nursing Science*. 2019;16(2):202-211. doi:10.1111/jjns.12234
  31. Wang J, Liu J, Li L, Man J, Yue S, Liu Z. Effect of education and muscle relaxation program on anxiety, depression and care burden in caregivers of acute stroke survivors A randomized, controlled study. *Medicine (United States)*. 2021;100(4). doi:10.1097/MD.00000000000024154
  32. Wanda Pereira Patrocínio. Autocuidado do cuidador e o cuidado de idosos. *Revista Kairós Gerontologia*. Published online 2015:99-113. doi:https://doi.org/10.23925/2176-901X.2015v18iEspecial18p99-113
  33. Soraya Santos dos Anjos S, Décio Abdalla Siqueira T, da Costa Herculano V. *A Importância Da Qualidade Psicológica Do Cuidador de Alzheimer*. Vol 7.; 2016.
  34. Edison dos Reisa, Marcia Maria Pires Camargo Novelli, Ricardo Luís Fernandes Guerra. Interventions conducted with groups of caregivers of elderly with dementia: a systematic review. *Cad Bras Ter Ocup*. 2018;26:646-657.
  35. Loi SM, Dow B, Ames D, et al. Physical activity in caregivers: What are the psychological benefits? *Arch Gerontol Geriatr*. 2014;59(2):204-210. doi:10.1016/j.archger.2014.04.001
  36. Batista MR, Batista JP, Furtado JC, et al. Efeito do exercício físico sobre a saúde e sobrecarga de mães de crianças e adolescentes com paralisia cerebral. *Revista Brasileira de Medicina do Esporte*. 2016;22(3):222-226. doi:10.1590/1517-869220162203110588
  37. Emma Alexandra Zamarripa Esparza, Blanca Mirthala Tamez Valdez, Manuel Ribeiro Ferreira. Repercusiones del cuidado informal en la vida laboral y personal de las mujeres cuidadoras. *REVISTA INTERNACIONAL DE TRABAJO SOCIAL Y BIENESTAR*. 2017;6:47-56.

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