

# RIASE

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## **EDUCATIONAL SUPPORT TO THE PERSON WITH STROKE AND FAMILY: A INTEGRATIVE LITERATURE REVIEW**

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## ABSTRACT

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**Objectives:** To identify, through the recent literature, the education and teaching activities carried out by nurses, capable of improving the person quality of life with Stroke and his/her family.

**Methodology:** Integrative review in the scientific databases MEDLINE Complete, Complementary Index e CINAHL® Complete of scientific articles published between 2008 and 2018, using the english descriptors "education and teaching activities in stroke", "quality of life" and "nursing care interventions"; "education", "stroke", "quality of life", "interventions" and "nursing".

**Results:** Were found 39 articles, of which 5 were considered pertinent to the integrative review from a protocol of research and analysis.

**Conclusions:** The educational and teaching activities developed by nurses that are capable of improving the person quality of life with stroke and his/her family go through teaching interventions related to stroke and its complications, new Stroke and associated complications, interventions related to self-care for the person with stroke and emotional and psychological support to the caregiver.

**Keywords:** Stroke; family; education; nursing interventions; quality of life.

## INTRODUCTION

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Advances in health care have allowed the survival of people with stroke in a home context, cared for by their families. However, the evidence suggests that such care is often difficult to achieve and caregivers are subject to high levels of overload and dissatisfaction related to the lack of information and support received both in terms of quality and quantity<sup>(1)</sup>. Several entities and organizations, such as the Portuguese Society of Stroke (SPAVC), have carried out campaigns to increase knowledge about stroke, specifically on the definition, symptoms and warning signs, risk factors, sequels and complications addressed to the general public<sup>(2)</sup>. Although its impact has been fundamental, the different ways of stroke awareness and its consequences has yet to be accepted as universally applicable and efficient<sup>(3)</sup>. Other studies<sup>(4)</sup>, also demonstrate that educational level, professional status and health status are independent factors for adequate knowledge about stroke, but as regards the inclusion of a family member or a caregiver, the evidence, it points in another sense.

According to *Guidelines for Adult Stroke Rehabilitation and Recovery of the American Stroke of American Heart Association/American Stroke Association (ASA/AHA)*, the inclusion of the family/caregiver in caring people with stroke is an integral component of rehabilitation. These *guidelines* also advocate that the support provided should cover education, training, counseling and the development of a support and a financial assistance structure. They also consider that the family member or caregiver must be involved in the decision-making and treatment planning as early as possible and throughout the rehabilitation process<sup>(5)</sup>.

In a qualitative study, that aimed to evaluate the transition of care in families who care for elderly people who suffered the first stroke episode<sup>(6)</sup>, the authors conclude that the elderly person who suffered a stroke goes through several stages, from hospital treatment to home care, and the transition to those care is a period in which families experience significant difficulties related to the new situation and may be related to both daily activities and more complex activities.

It is justified thus a greater understanding of the importance of teaching and training performed by nurses and in particular those carried out by nurses specialist in rehabilitation nursing. For Dean-Baar<sup>(7)</sup>, in rehabilitation, the educational process promotes self-care, helping the family to acquire new skills, competently applying knowledge and skills to functional activities and developing adaptive behaviors in order to deal with illness or incapacity, avoiding the aggravation of the same.

The overload of work in the relatives of victims of stroke represents an important factor concerning their quality of life<sup>(8)</sup>. Nursing interventions, including educational and support interventions, to the family/caregivers of the person, initiated during hospitalization have the primary objective of ensuring humanized care, well-being and quality of life promotion and recovery of the person<sup>(9)</sup>.

For the World Health Organization (WHO)<sup>(10)</sup> quality of life has been defined as an individual perception of each one, in their position in life in the cultural context and of the values systems where they are inserted, in relation to their objectives, expectations, standards and concerns. This concept encompasses four dimensions of health<sup>(11)</sup>: physical dimension, that is, somatic sensations, symptoms of the disease and side effects of treatment; the mental dimension of health, variable, from a positive sense of well-being to non-pathological forms of psychological suffering necessary to diagnose psychiatric disorder; social health, which includes the assessment of quantitative and qualitative aspects of contacts and social interactions and the functional dimension of health that includes both the physical functioning in terms of self-care, mobility and level of physical activity, as well as the social role function in relation to family and work.

For Kalra and his collaborators<sup>(12)</sup>, one of the important aspects of stroke rehabilitation is to bridge the gap between survivor and caregiver recovery expectations and residual disability to promote the overall well-being of stroke survivors and of their families. These authors also point out that the training of the caregivers in basic handling and handling skills, facilitation of daily living activities and simple nursing tasks reduces the burden of care and improves the quality of life of the stroke survivors and of their caregivers<sup>(12)</sup>.

Bearing in mind the aspects presented by Kalra and his colleagues<sup>(12)</sup> and the recommendations of the Guidelines for Adult Stroke Rehabilitation and Recovery of the AHA/ASA<sup>(5)</sup>, regarding the benefits of inclusion of the family member/caregiver in the care of people with stroke as an integral component of rehabilitation, the objectives of this integrative systematic review were to identify, through the recent literature, the education and teaching activities carried out by nurses capable of improving the quality of life of the person with stroke and his/her family and synthesize the information collected, evidencing the activities most frequently performed by the rehabilitation nurses.

## METHODOLOGY

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According to Thompson and collaborators<sup>(13)</sup> evidence-based practice may take the following steps: defining the clinically significant issue in response to a recognized need for information; research of the most appropriate evidences; critical analysis of selected evidence; integration of evidence into a strategy of action and intervention; and finally evaluation of the effects of the actions and decisions taken.

Following these steps, we resorted to the PICO research protocol. The PICO mnemonic includes population description (P), intervention (I), comparison (C) and outcome (O) or outcome of interest<sup>(14)</sup>. These components of the question, with the additional specification of the type of study design to be included, form the basis of pre-established eligibility criteria for the review<sup>(15)</sup>.

So, starting from the question “*What education and teaching activities developed by nurses (rehabilitation nurses) (I) can contribute to improving the quality of life (O) of the person with stroke and his or her family (P)?*”, the participants were people with stroke and their families, the interventions were teaching and training activities carried out by nurses, and the results were the improved in quality of life (table 1).

Table 1 – Protocol for research and articles analysis.

P	Person with stroke and his /her family
I	Education and teaching activities developed by nurses (rehabilitation)
C	Comparisons if they exist
O	Improvement of quality of life

The PICO research protocol that guided the definition of the question was also used to analyse articles subject to revision.

The articles under study were obtained through an exhaustive research in the online scientific databases, namely in the online search engines B-on and EBSCO. In the B-on the descriptors "education and teaching activities in stroke" and "quality of life" and "nursing care interventions" were used, and the boolean search operator AND was used. In the EBSCO search engine the descriptors used, structured by the DeCS vocabulary (health descriptors), the descriptors "education", "stroke", "quality of life", "interventions" and "nursing" as boolean search operator was used AND.

Table 2 shows the inclusion and exclusion criteria for the selection of articles for review:

Table 2 – Inclusion and exclusion criteria for article selection.

	Inclusion Criteria	Exclusion Criteria
Population	People with stroke and/or family in adulthood.	People with other conditions, or family members under the age of 18.
Intervention	All the education and teaching activities developed by nurses in a hospital or home context.	All activities developed by nurses outside the scope of education and training or activities developed by other health professionals.
Comparison	Comparison, if applicable, of the interventions under study with interventions considered by the authors as usual.	Not applicable.
Outcome	Studies whose outcome has an impact on the quality of life or any dimension related to it.	Studies whose outcome has no impact on the quality of life, or any dimension associated with it.

The articles published in the last 10 years (2008 – 2018) were considered in both search engines, considering the number of scientific articles found in the last 5 years. Full-text articles with free access, relevant to the review, were included. Initially, the B-on search engine was searched, resulting in 8 articles, of which 2 were included by title, abstract and full text reading (MEDLINE Complete and Complementary Index databases) and 6 excluded by title. In the EBSCO search engine, 31 articles were found, of which 9 were included by title and after reading the abstract or full text, 4 articles were included (MEDLINE Complete and CINAHL® Complete databases), 1 article had already been identified in the previous research. In total 5 articles were included for review. Based on the hierarchy of evidence<sup>(16)</sup> these were studies of systematic review<sup>(17)</sup>, integrative review<sup>(18)</sup>, randomized controlled clinical studies (RCT)<sup>(19,20)</sup>, and non-randomized clinical study<sup>(21)</sup>. The research strategy of articles to be reviewed, was synthesized in the following scheme (figure 1):

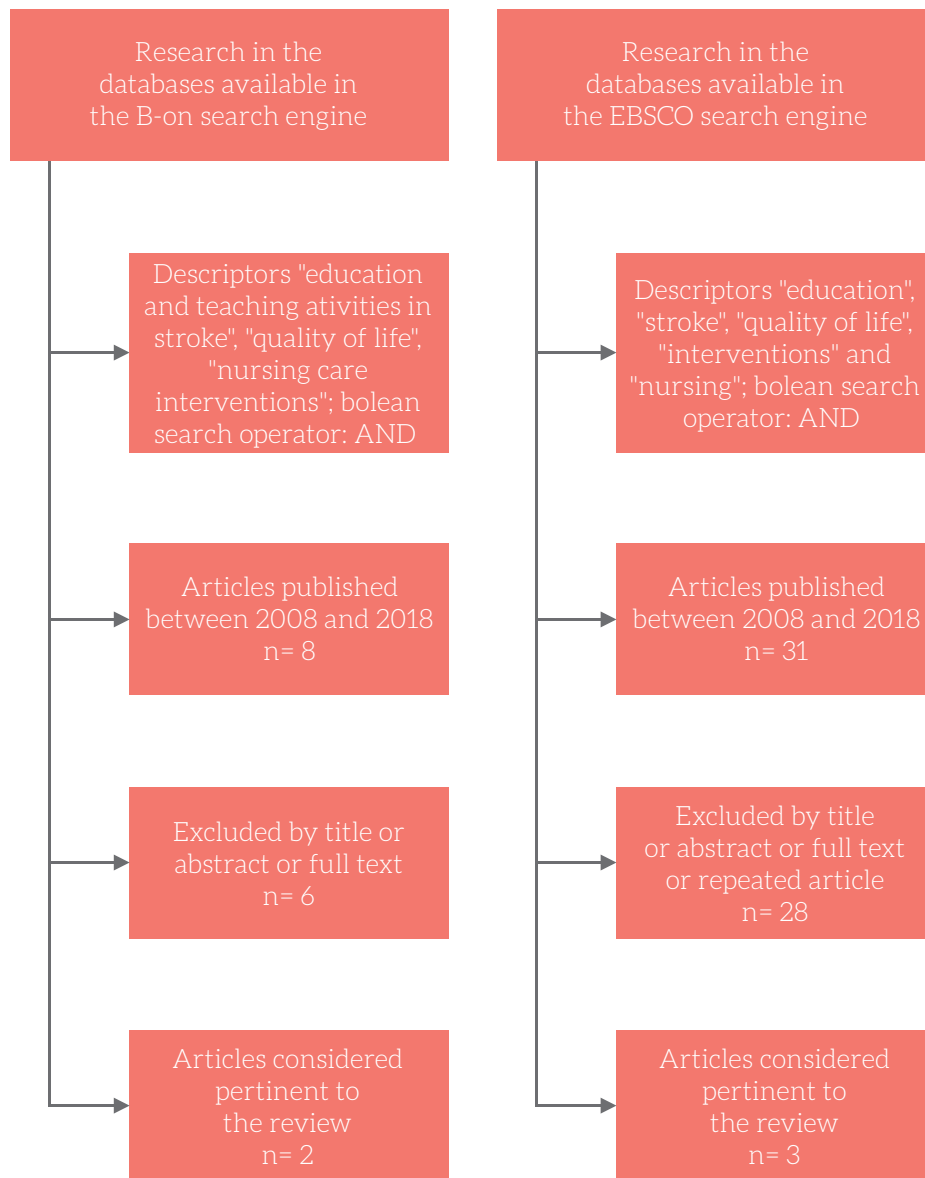


Figure 1 – Article search strategy for review.

Regarding the extraction of data from the articles included in this review, the PICO protocol was used as a strategy, also used as a starting point for formulating the question of this literature review.

## RESULTS

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Of the 5 articles relevant to the review, one was a systematic review<sup>(17)</sup>, another an integrative review<sup>(18)</sup> and two were randomized controlled clinical studies (RCT)<sup>(19,20)</sup> and one was a non-randomized clinical trial, with convenience sample<sup>(21)</sup>. The results of these studies are presented in the table 3.



Table 3 – Summary of the reviewed studies result.

Identification of the study	Study design and purpose	P Participants	I Intervention or phenomenon of interest	C Comparisons	O Results (Outcomes)
<p>1. "Nursing Interventions to The Patient With Stroke In Rehabilitation"<sup>(18)</sup></p>	<p>Integrative review. Objective: to know the interventions implemented by nurses in the care of patients with stroke in the rehabilitation phase.</p>	<p>People with stroke in rehabilitation.</p>	<p>Motor and functional rehabilitation; evaluation of physiological functions and prevention of complications; emotional care; care related to activities of daily life; care related to urinary incontinence and bladder catheterization; prevention of pressure ulcers; oral hygiene care; positions; fall prevention Education on the disease and its implications, on stroke prevention, nutritional care <i> coping strategies.</i> Coordination of care and follow-up, multidisciplinary care, referral for discharge and community services. Caregiver guidance on the disease and rehabilitation process, caregiver training on various person care, and on stroke prevention.</p>		<p>The nursing interventions of motor and functional rehabilitation stand out; person education and caregivers about the disease and how to deal with it in order to have a better health and prevent a new stroke.</p>

Table 3 – Summary of the reviewed studies result.

Identification of the study	Study design and purpose	P Participants	I Intervention or phenomenon of interest	C Comparisons	O Results (Outcomes)
<p>2. "Effectiveness of educational nursing home visits on quality of life, functional status and care dependency in older adults with mobility impairments: a randomized controlled trial"<sup>(19)</sup></p>	<p>Randomized controlled trial Objective: to determine the effectiveness of educational home visits in the quality of life and dependency of care in the elderly with impairment of mobility.</p>	<p>Participants with functional disabilities (including stroke sequelae) in their usual settings N= 52 (24 in the intervention group and 28 in the control group).</p>	<p>Home visits, counseling, training and education on mobility and quality of life issues, for example, prevention of falls or satisfaction with the current state of health. Including telephone follow-up between visits. Mobility education in a multidimensional approach (such as activity, functional mobility and subjective dimension).</p>	<p>The control group did not receive the mentioned interventions. Just the usual care and treatments.</p>	<p>Individuals who completed the study had a better psychological quality of life and less reliance on care than those who dropped out. The overall mean quality of life and dependence of participants at the start of the study was lower in the control group than in the intervention group, conditioning the study.</p>

Table 3 – Summary of the reviewed studies result.

Identification of the study	Study design and purpose	P Participants	I Intervention or phenomenon of interest	C Comparisons	O Results (Outcomes)
<p>3. "Effectiveness of Supportive Educative Learning programme on the level of strain experienced by caregivers of stroke patients in Thailand"<sup>(21)</sup></p>	<p>Non-randomized study conducted in two different hospitals (one for the other intervention for control group) Objective: To develop and implement a Supportive Education Program for family caregivers (SELF) of stroke survivors, and to evaluate its effect on the stress and quality of life of family caregivers.</p>	<p>Caregivers/ relatives of people with stroke N= 140 (70 intervention group and 70 control group) admitted to the stroke study hospitals.</p>	<p>Interactive group sessions, including discussion and practice. Topics addressed: Stroke and its complications (pressure ulcer, shoulder pain, respiratory infection and contractures) and prevention of strokes; prevention of new stroke; maintenance of adequate hydration and nutrition, identification of difficulties in swallowing and safe swallowing; nasogastric tube and gastrostomy (PEG) manipulation; bladder and bowel function; bladder catheter care, bladder and bowel elimination training; positioning, mobility and transfers; role of the family caregiver and teaching the same to their own self-care. Provided written information on these topics to caregivers. After discharge, periodic telephone calls during the intervention to discuss problems, suggestion of care and support to the caregiver.</p>	<p>People with stroke and their caregivers received the usual care provided by the hospital and health service.</p>	<p>Educating and supporting family caregivers of stroke survivors can reduce the stress of the caregiver and improve their quality of life.</p>

Table 3 – Summary of the reviewed studies result.

Identification of the study	Study design and purpose	P Participants	I Intervention or phenomenon of interest	C Comparisons	O Results (Outcomes)
<p>4. "Stroke Caregiver Outcomes from the Telephone Assessment and Skill-Building Kit (TASK)"<sup>(20)</sup></p>	<p>Randomized controlled trial Objective: To determine the preliminary effectiveness of the TASK program in improving outcomes (optimism, task difficulty, threat assessment, depressive symptoms, daily life changes, and general health precepts) of stroke survivors Caregivers.</p>	<p>Caregivers of stroke survivors from a rehabilitation hospital and three acute care hospitals. N= 40 (N= 21 TASK Intervention and N= 19 control group).</p>	<p>Developed written material with guidelines and information on stroke, management of survivors' emotions and behaviors, provision of physical and instrumental care, management of personal responses while providing care (TASK). Sending caregivers of this written material with stress management strategies to the stroke survivor and caregiver, as well as leaflet on the care of the American Stroke Association (ASA) Telephone calls from a nurse, facilitating the assessment of caregivers' skills, from individualized interventions that addressed the needs of priority skills identified by the caregiver.</p>	<p>In the control group, caregivers received written material on stroke survivor care (ASA) and weekly nurse calls. In the control group only, active listening was provided without advice or information other than telling them to contact their usual health care provider or contacting the ASA for additional materials.</p>	<p>Significant increases in optimism, less task difficulty and in threat assessment in the TASK group were demonstrated in relation to the control group.</p>

Table 3 – Summary of the reviewed studies result.

Identification of the study	Study design and purpose	P Participants	I Intervention or phenomenon of interest	C Comparisons	O Results (Outcomes)
<p>5. "Nursing intervention studies on patients and family members: a systematic literature review"<sup>(17)</sup></p>	<p>Systematic review. Objective: to carry out a review of studies on nursing intervention in patients and their families, and the main focus of the study was on the goals, methods and impacts of these interventions.</p>	<p>People and families with chronic disease. (Including Stroke).</p>	<p>Support Interventions; involving a teaching component; and counseling; education interventions involving a support component.</p> <p>Support interventions focus on the sharing of emotions and experiences and peer support implemented by a nurse.</p> <p>Interventions included lectures and written materials on disease, rehabilitation, management, and symptom prevention.</p> <p>Training interventions in various practical skills to facilitate the delivery of patient care. The identified interventions can improve mainly physical and mental health as well as functional capacity (symptoms of illness, overload, depression, social functioning, etc.)</p>		<p>The identified interventions can improve mainly physical and mental health as well as functional capacity (symptoms of illness, overload, depression, social functioning, etc.).</p>

## DISCUSSION

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With a variable number of participants (between 40 and 140), all adult stroke survivors and their family/caregiver, the analyzed articles, had in common the fact that they wanted to identify the education and teaching activities carried out by nurses, who could improve quality of people with stroke and their families, objectives overlapping this work.

Two of these studies were randomized controlled trials<sup>(19,20)</sup> and one non-randomized<sup>(21)</sup>, conducted in two different hospitals what made possible to make comparisons, regarding teaching activities and non-performance of the same, conclusions to which the two literature reviews also converged.

The review by Cavalcante et al.<sup>(18)</sup> concluded that nursing interventions at people with stroke in the rehabilitation phase were mainly educational interventions on disease, treatment, prevention, rehabilitation and aimed training mobility and life activities. And the review of Matilla and collaborators<sup>(17)</sup> focused on the activities developed with family members relatives of people affected by stroke and other chronic diseases were also centered on educational interventions on the same aspects, thus reinforcing what Kalra et al.<sup>(12)</sup>, that one of the most important aspects of the rehabilitation of people with stroke is the training of caregivers in basic skills of movement and facilitation of activities and daily life simple tasks capable of reducing the burden of care and improving the person quality of life of survivor of stroke and his caregivers.

Regarding the reviewed clinical studies, all involved a concrete intervention among groups of participants whose result was compared with the control group<sup>(19,20,21)</sup>. Buss et al.<sup>(19)</sup> focused on educational home visits and concluded that the interactive sessions, with written and telephone support, have improved the quality of life and care dependence of elderly people with mobility deficits. Oupra et al.<sup>(21)</sup> developed and implemented a system of support and education for family caregivers of stroke survivors through interactive group sessions, including discussion and practice, as well as by providing written and telephone information on strategies and skills to be developed by caregivers of stroke survivors, highlighting as benefits of this information a reduction of tension and improve the caregiver's quality of life. These data point to what Dean-Baar's<sup>(7)</sup> defended, emphasizing the importance of the educational process in rehabilitation and its benefits in promoting self-care, helping the family acquire new skills by competently applying knowledge and skills to functional activities, developing adaptive behaviors in order to deal with the illness or incapacity, thus avoiding the aggravation of the same.

And the study by Bakas and colleagues<sup>(20)</sup> sought to determine in their study the preliminary effectiveness of a telephone evaluation program and a set of written guidelines for skills development, improvement of outcomes (such as optimism, task difficulty, threat assessment, depressive symptoms, changes in daily life) of caregivers of stroke survivors.

In all the articles reviewed it is clear the importance of nurses' intervention, especially with their role in caregiver education. Most of the interventions focus on the perceptions of the family/caregivers, on how interventions interfere in several aspects related to the various dimensions of life quality<sup>(17,18,19,20,21)</sup>. In the reviewed articles, the mentioned interventions are focused on teaching, training and emotional support received both at the hospital level<sup>(20,21)</sup> and at the home level (by telephone or in person)<sup>(19,20,21)</sup>.

Nursing interventions in education or teaching can be transmitted through lectures or individual or group training sessions<sup>(17,21)</sup> or by phone<sup>(20)</sup> or the two components<sup>(17,18,19,20)</sup>. The usefulness of associating with the teaching activity the provision of written information material to caregivers<sup>(17,19,20,21)</sup>.

These educational interventions are aimed at facilitating the care of the person with stroke and are given a better understanding of the illness achieved by clarification about stroke, prevention of complications, guidance on the rehabilitation process and prevention of a new event<sup>(17,18,20,21)</sup>. They included teaching activities related to maintenance of adequate hydration and nutrition, maintenance of safe swallowing, handling of NGI and gastropathy (PEG). And they covered teachings about bladder and bowel function. Some authors have also addressed the teachings related to mobility, placements and transfers<sup>(18,20,21)</sup> and the respective caregiver training. Caregiver training, according to Oupra et al.<sup>(21)</sup>, requires the acquisition of knowledge such as pressure ulcer, painful shoulder, respiratory infection and contracture, as well as prevention of these complications. The authors<sup>(21)</sup> also highlight the importance of teaching about the role of the caregiver, as well as of his own self-care.

The nursing interventions on mobility identified were referred to in a multidimensional perspective, namely mobility as activity, functional mobility and the subjective dimension of mobility<sup>(19)</sup>. And teaching interventions related to stress management strategies and emotional support for the stroke survivor and caregiver were considered extremely important<sup>(17,21)</sup>.

Nurses, as educators, train the caregivers and people with stroke, helping them to solve and deal with the problems they face. These should recognize the factors that facilitate or hinder learning and conduct it in a way that provides quality care, improves health and prevents a new stroke<sup>(18)</sup>.

Quality of life, independently of its individual subjectivity, can be considered a synonym for health, encompassing aspects such as functionality, the consequence of daily health status, mental and emotional health, and lifestyle<sup>(22)</sup>. Thus, the support and education interventions addressed in the reviewed studies aim to achieve outcomes that directly or indirectly aim to promote the quality of life and with this also the promotion of health.

By allowing rehabilitation nurses skills that enable them to prevent complications and maximize people's potential<sup>(23)</sup>, education, training, and support provided to caregivers can allow the development of rehabilitation skills<sup>(21)</sup>. Nursing interventions should be based on the active involvement and learning of the participants, encouraging them to create strategies to respond to different situations<sup>(17)</sup>.

### *Review Limitations*

It was not possible to attribute these activities to specialists' nurses in rehabilitation nursing, because as an area of nursing specialization it exists in a few countries. On the other hand, the scarcity of original articles also conditioned the research, leading to include in this literature review systematic reviews.

## CONCLUSION

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This integrative review allowed to identify the education, teaching and training activities carried out by nurses and that can improve the quality of life of the person with stroke and his/her family. Although the articles submitted for review do not refer to nurses who are specialists in rehabilitation nursing, possibly because specialization as a professional category it exist in a few contries, due to their competencies and differentiated intervention, nurses specialized in rehabilitation nursing are particularly qualified to promote preventive actions and measures to ensure the maintenance of people's functional capacities, prevent complications and avoid disabilities, and provide therapeutic interventions aimed at improving residual functions, maintaining or restoring people's independence in life activities, and minimizing the impact of disabilities<sup>(23)</sup> both for oneself and for their caregivers.



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