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Adaptation Processes of Survivors and Informal Caregivers after Stroke: A Scoping Review through the Lens of Educational Sciences

Ana Moura ^a, Patrícia Magalhães^a, Sofia Castanheira Pais^a, and Elisabete Alves^{a,b}

^aUniversity of Porto; ^bUniversity of Évora

ABSTRACT

Background: Systematic knowledge about stroke adaptation can be a useful tool to develop evidence-based policies and practices centered on survivors and informal caregivers.

Purpose: This scoping review summarizes the body of knowledge about the adaptation processes after stroke.

Methods: Based on PRISMA-ScR guidelines, databases were searched, in November 2021, and 14 studies were included. The qualitative findings were inductively synthesized. The quantitative results were included in the taxonomy of categories and themes of the qualitative analysis.

Results: The adaptation processes after stroke are constituted by psychosocial and structural adaptation. The emotional distress, the use of emotional-based coping strategies, the received social support, the role and relationship changes, and the social participation were central factors of the psychosocial adaptation. Regarding the structural adaptation, the use of problem-solving based coping strategies; the centrality of the caregiving role; the learning processes; and the changes in daily life activities were reported.

Discussion: Health education research and interventions after stroke should consider the role of adaptative coping strategies, social support networks and services, and long-term educational policies.

Translation to Health Education Practice: This work will assist Health educators and researchers to deeper understand the adaptation after stroke, identify knowledge gaps, and define further research issues.

ARTICLE HISTORY

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Background

Research in education has been expanded its concerns to plural and interdisciplinary fields, where Health education occupies a central role.¹ However, literature has focused essentially on the relationship between education levels and health outcomes and on health promotion, with little investment in social and educational processes adjacent to adaptive phenomena in the context of chronic conditions.^{1,2}

Worldwide, stroke is one of the leading causes of long-term disability, being one of the health conditions with the highest proportion of disability-adjusted life years.³ The decrease in stroke mortality rates observed in the last decades,^{4,5} led to an increase in the number of survivors, with reduced motor, sensory and/or cognitive functions and with psychological and social sequelae.^{6–8} After discharge, most stroke survivors return home, often requiring the assistance and support of an informal caregiver. These unpaid workers need to adjust to the immediate and long-term effects that require the varying degrees of care, experiencing the psychological and socio-economic repercussions of stroke.⁹

The chronic phase of stroke and its medium and long-term consequences is conceptualized as a major disruptive life experience, not only for the survivors but also for their close relatives,¹⁰ mainly due to its unexpected, unpredictable, and impactful nature.¹¹ The limitations caused by stroke and the consequent routines changes in the stroke survivors and informal caregiver's personal, professional, and social activities negatively impacts their quality of life (QoL), defined as an individual's perception of their position in life,¹² and require responses to new daily demands at individual, peer, and social levels.^{13–15} Such adaptative responses – consequence of coping efforts, denoting mastery and adjustment to answer to problems or new challenges – are predominantly experiential, occurring in a disorderly way and presenting the capacity to continually renew themselves, since individual and social life is unpredictable and is in continuous change.¹⁶ The adaptation process occurs when the individual mobilizes a series of behaviors and mental processes to neutralize the stress experience and reestablish the integrity of function, which involves achieving a balance between “perceived demands” (stress) and “marshalled resources” (coping),

contributing to reduce anxiety and enhance well-being.^{17,18} The way in which adaptation processes are triggered and experienced has consequences not only in the disease management but also in the QoL of these individuals. Because of the possible consequences of these processes (e.g., social exclusion and low social participation,¹⁹) research and practices should understand and facilitate the adaptation after stroke, in order to ensure and/or to improve the QoL and well-being of survivors and caregivers. In this sense, systematic knowledge regarding the adaptation of stroke survivors and informal caregivers can be a useful tool, contributing to promote the implementation of evidence-based social and educational policies and practices. This may allow equitable access to social support, information, educational and training opportunities directed to survivors and caregivers to develop their adaptation skills. However, studies that map the body of knowledge in this field are scarce, hindering the deep understanding of the research problem and the development of recommendations and strategies to sustain and enable the adaptation after a stroke.

Purpose

The purpose of this study was to summarize the literature on the adaptation processes after stroke. Specifically, the following research question was designed: “What is the body of knowledge regarding the adaptation processes of stroke survivors and informal caregivers?.” This work will promote a deeper understanding of the adaptation processes, identifying knowledge gaps and defining further research issues.

Methods

Protocol

This scoping review was conducted and reported based on the Preferred Reporting Items for Systematic reviews and

Meta-Analysis extension for Scoping Reviews (PRISMA-ScR) guidelines.²⁰ A review protocol was developed in advance but was not registered or published prior to conducting the review. The quality appraisal of studies was not conducted since: 1) this review aims to explore the general scope of research conducted regarding the adaptation processes after stroke; 2) there is a lack of methodological robustness of the studies that hinders a rigorous quality assessment process. Four electronic databases were searched for original articles, in November 2021. The search strategy is described in detail in [Table 1](#).

Selection of sources of evidence

The first and second authors independently screen all the papers retrieved initially, first based on the title and abstract, and afterward, based on the full texts. Publications with titles and abstracts lacking adequate information to determine inclusion/exclusion criteria underwent full-text review. The process was cross-checked in both phases. An almost perfect strength of agreement was achieved [total percentage of agreement = 98.9%; Cohen’s kappa = 0.87; 95% confidence interval (95% CI) 0.81–0.92]. The last author resolved conflicts when consensus was not previously achieved and supervised decisions on eligibility.

Data extraction

A descriptive analysis of the characteristics of the included literature was conducted ([Table 2](#)). A standardized data extraction sheet was developed and completed by A.M. and P.M., capturing data on study design, type of methodology, authorship, publication year, country, period of data collection, timing of data collection, setting, participants and sample size, and data collection instruments. Such main characteristics were selected since they are frequently reported in review studies and were described in most of the studies included.

Table 1. Search strategy.

Research question	What is the body of knowledge regarding the adaptation processes of stroke survivors and informal caregivers?
Search expression	((adaptation) OR (transition) OR (management) OR (rehabilitation) OR (education) OR (learning) OR (training)) AND ((stroke) OR (brain vascular accident) OR (cerebrovascular accident) OR (post-stroke) OR (post stroke) OR (poststroke) OR (transitional care) OR (discharge planning) OR (care-coordination) OR (continuity of care) OR (long-term care) OR (follow-up after discharge)) AND ((survivor*)) AND ((caregiver*) OR (informal caregiver*) OR (carer*) OR (primary caregiver*) OR (caregiving) OR (family caregiver*) OR (spouse caregiver*))).
Electronic databases	PubMed, ISI Web of Science, PsycINFO and SciELO were searched for original articles with no restrictions set for language or time of publication.
Eligibility criteria	Inclusion criteria: only empirical, peer-reviewed, original full-length studies that reported data on the adaptation processes after stroke and comprised adult survivors and/or informal caregivers were included (≥ 18 years old). Exclusion criteria: 1) non-original full-length studies (reviews, meta-analyses, study protocols, comments, editorials, newspapers articles, conference proceedings and abstracts, reports, guidelines and gray-literature, scales validations and randomized control trials); 2) studies focusing on formal/paid caregivers; 3) studies whose focus were not the adaptation processes of stroke survivors and/or informal caregivers; 4) articles written in languages other than English, French, Spanish or Portuguese.

Table 2. Main characteristics of the included studies (n = 14).

Publication	Country	Period of data collection	Timing of data collection	Setting	Participants and sample	Data collection instruments
Qualitative studies						
Cross sectional studies						
O'Connell and Baker, 2004	Australia	-	-	Acute hospital setting, rehabilitation, and community	37 informal caregivers	Semi-structured interviews
Smith et al., 2004	Scotland	2000–2001	1 year after stroke	Community	90 informal caregivers	Semi-structured interviews
Buschenfeld et al., 2009	UK	-	2 to 7 years after stroke	Community	7 informal caregivers	Semi-structured interviews
Saban and Hogan, 2012	USA	-	3 to 12 months after stroke	Community	46 informal caregivers	Open-ended questions
Pringle et al., 2013	UK	-	1 month after hospital discharge	Community	12 dyads (stroke survivors and informal caregivers) ¹	In-depth interviews and self-report diaries
Taha and Kazan, 2015	Lebanon	Between January and July 2012 ²	6 to 12 months after rehabilitation	Community	6 informal caregivers	Interviews
Woodford et al., 2017	UK	-	-	Community	19 informal caregivers	Semi-structured interviews
Ytterberg et al., 2017	Sweden	-	6 years after stroke	Community	7 informal caregivers	Semi-structured interviews
Torregosa et al., 2018	USA	Jun-15	-	Community	11 stroke survivors and 8 informal caregivers	Focus-group
Longitudinal studies						
Jongbloed, 1994	Canada	-	5, 9, 14, 20 and 29 months after stroke	Community	1 dyad (stroke survivor and their informal caregiver)	Semi-structured interviews ³
Quantitative studies						
Cross sectional studies						
King et al., 1995	USA	-	Prior to discharge from inpatient rehabilitation	Community	26 dyads (stroke survivors and informal caregivers)	Semi-structured interviews
Longitudinal studies						
King et al., 2001	USA	-	Prior to discharge from acute rehabilitation (T1) and 6 to 10 weeks after discharge home (T2)	Rehabilitation	136 informal caregivers	Questionnaire ⁴
King et al., 2002	USA	-	Prior to discharge from acute rehabilitation (T1), 6 to 10 weeks after discharge home (T2), 1 year (T3) and 2 years after discharge (T4)	Rehabilitation	53 stroke survivors	Questionnaire ⁴
Rochette et al., 2007	Canada	-	2 weeks (T1) 3 months (T2) and 6 months (T3) after stroke	Community	88 stroke survivors and 47 informal caregivers	Questionnaire ⁵

¹Although one survivor reported the existence of two caregivers, the total sample included only one significant caregiver.

²Validation interviews were carried out between March and April 2013.

³Case study.

⁴Adaptation outcomes were assessed using the Center for Epidemiologic Studies – Depression Scale and physical health rates.

⁵Appraisal (primary and secondary) was measured with the Stress Appraisal Measure, coping strategies were measured using the Revised Ways of Coping Questionnaire (RWCO) and participation in daily activities and social roles was measured using the Assessment of Life Habits (LIFE-H 3.0, short version).

The main qualitative findings regarding the adaptation processes of stroke survivors and informal caregivers were retrieved and inductively synthesized into themes and categories by A.M., according to Stemler' protocol for content analysis.²¹ A triangulation strategy was used to guarantee the rigor and quality of research – P.M. and E.A. collaborated in the development and validation of the coding framework. The quantitative results were synthesized and were deductively included in the taxonomy of categories and themes of the qualitative analysis.

Results

Selection of sources of evidence

From the 2 854 records initially retrieved, 1 825 were screened based on title and abstract, and 1 759 records were excluded (Figure 1). The full text of the remaining

66 papers was assessed and 14 were considered eligible for final analysis. A backward reference tracking was carried out, however, no additional papers met the inclusion criteria.

Characteristics of sources of evidence

Research design

Of the 14 included articles, the majority (n = 10) had a qualitative design (Table 2). Ten studies were cross-sectional and four were longitudinal. Only three studies provided information regarding the period of data collection, ranging from one month to one year. The timing of data collection ranged from prior to discharge from inpatient rehabilitation to seven years after stroke.

Most studies recruited the participants exclusively from the community (n = 11), few recruited from the rehabilitation settings (n = 2) and only one combined the

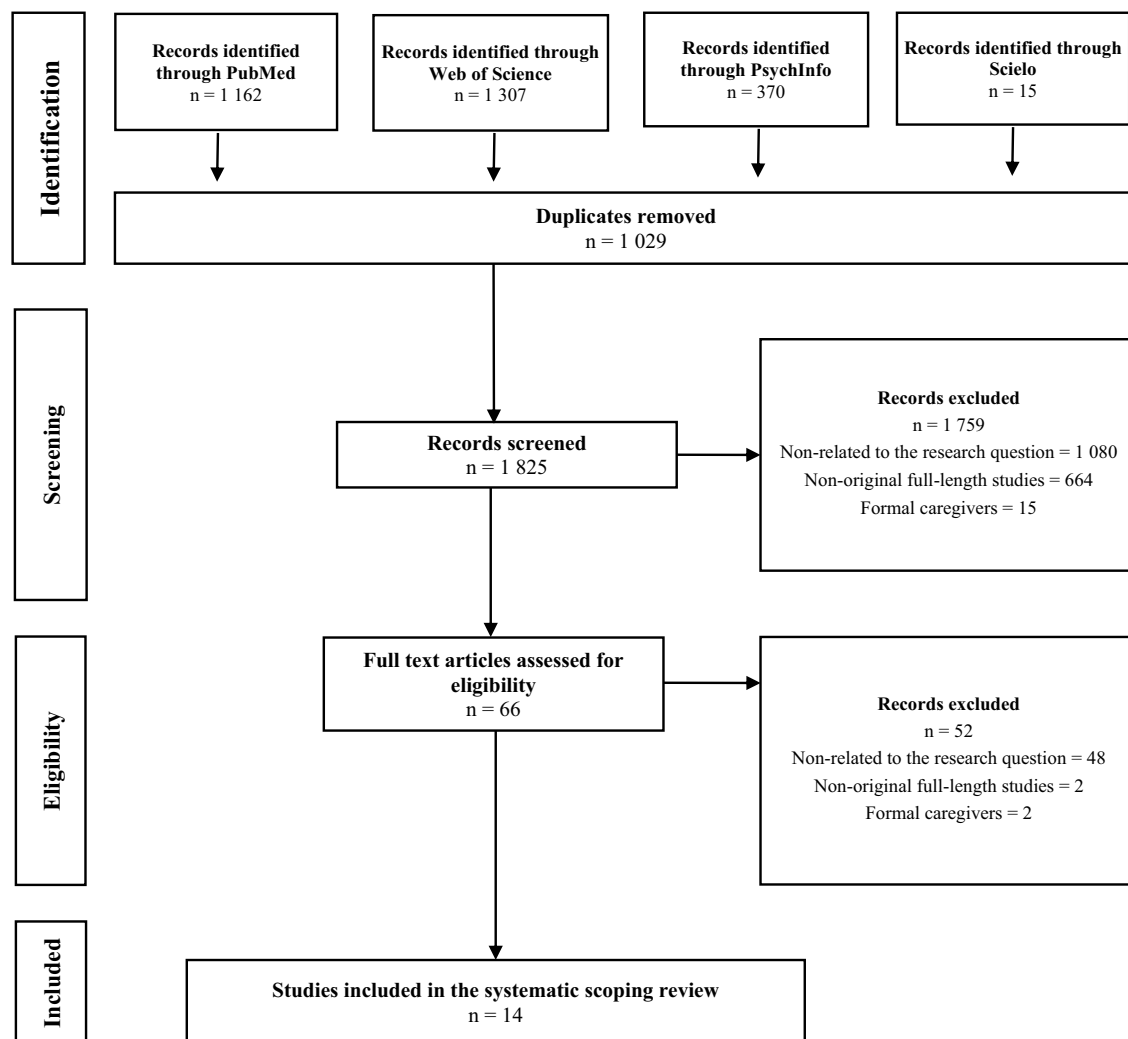


Figure 1. Flowchart of the selection of sources of evidence.

acute hospital setting, rehabilitation, and community. The data was collected mostly through interviews (n = 8), and questionnaires (n = 3). One study used open-ended questions, other focus groups, and another one combined in-depth interviews with self-reported diaries.

More than half of the studies were conducted in the United States of America (n = 5) and in the United Kingdom (n = 3). Although the range of publication years varied between 1994 and 2018, it should be noted that most studies were developed from 2000 onwards (n = 12) (Table 2).

Participants and sample

The samples of the included studies were composed by informal caregivers only (n = 8), dyads of stroke survivors and their caregivers (n = 3), stroke survivors and informal caregivers who were not dyads (n = 2), and stroke survivors only (n = 1) (Table 2). Considering the baseline data of the included studies, the sample sizes ranged from 2 to 136 participants.

In general, studies reporting data on adaptation after stroke included female rather than male participants (data not shown). Studies that reported data on informal caregivers were developed with a greater proportion of female participants, with one including exclusively female caregivers.²² Only one study was composed entirely by stroke survivors included more male participants (34 males vs. 19 females), and one study did not report data regarding the sex of participants.

The age of participants across studies ranged from 18 to 89 years old (data not shown).

Synthesis of results

Two common central dimensions emerge: the psychosocial adaptation, which includes emotional and social-

based mechanisms; and the structural adaptation focused on daily life needs and strategies (Figure 2).

Psychosocial adaptation

The emotional distress of informal caregivers and stroke survivors emerges as a central dimension of the psychosocial adaptation for both (Table 3). The studies reported that informal caregivers often feel guilty, namely, blaming themselves for the stroke and the lack of attention to the survivor before the stroke. After the stroke, they also frequently reported an inadequate fulfillment of a perceived family obligation. Additionally, caregivers described conflicting emotions, discomfort (e.g., with the partner nakedness), inability to be spontaneous, and feelings of loss regarding their life plans or their relationships.^{11,22-31} Stroke survivors frequently reported emotions such as frustration and anger, as well as loss of self-confidence.^{11,22,27,28}

Also, emotional-based coping strategies to overcome difficulties were reported as an adaptive mechanism. Informal caregivers tend to deal with their new caregiving role by accepting the permanence of their changed life, focusing on altruism, avoiding emotional expression, resorting to humor, and using religious-based convictions.^{22-25,27,29,32,33} With less expression, survivors mobilize coping strategies such as resorting to humor and “willpower” to overcome post-stroke challenges.^{27,30,32,34} Only one study reported sleep disturbances as an aspect that informal caregivers had to adapt.²⁸

The social-based mechanisms of the adaptation focused mostly on social support and role changes. The studies revealed the centrality of receiving formal and informal support on the adaptation for both caregivers and stroke survivors.^{11,22,25,31} The importance of having help on bureaucratic issues, such as require

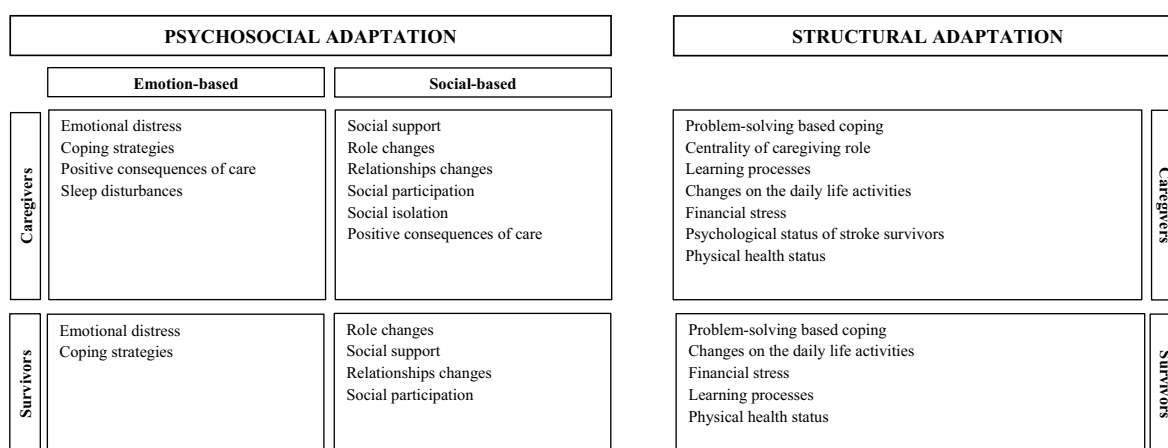


Figure 2. Taxonomy of the themes and categories.

Table 3. Adaptation to stroke and informal care: synthesis of the studies results.

		Caregivers	Survivors
Psychosocial adaptation	<i>Emotion-based</i>		
	Emotional distress	<ul style="list-style-type: none"> • Guilty, conflicting emotions discomfort; inability to be spontaneous, feelings of loss. 	<ul style="list-style-type: none"> • Frustration, anger, loss of self-confidence.
	Coping strategies	<ul style="list-style-type: none"> • Acceptation of a changed life; focus on altruism, avoidance of emotional expression, resort to humor, use of religious-based convictions. 	<ul style="list-style-type: none"> • Resort to humor and “willpower”.
	Positive consequences of care	<ul style="list-style-type: none"> • Closely united partnership with the stroke survivors, growth and self-improvement, development of feelings of belonging and well-being. 	
	Sleep disturbances	<ul style="list-style-type: none"> • Inability to “switch off”, provision of permanent assistance. 	
	<i>Social-based</i>		
	Social support	<ul style="list-style-type: none"> • Help on bureaucratic issues, care needs, and daily-life activities. • Emotional support. • Support on accessibility (e.g. transportation and ramps). • Lack of formal and informal networks. • Barriers to access: provision of incorrect information, inability to ask for support, lack of general practitioner’s recognition. • Feeling misunderstood and unsupported by family and friends. 	<ul style="list-style-type: none"> • Support from immediate caregivers and extended networks.
	Role changes	<ul style="list-style-type: none"> • Giving up roles and activities of importance and value. • Alterations in house management responsibilities. • Family roles changes. 	<ul style="list-style-type: none"> • Inability to perform tasks and to assume previous responsibilities. • Not returning to work.
	Relationship changes	<ul style="list-style-type: none"> • Changes in family (especially marital relationships) and friends’ dynamics. • Love, intimacy, and sexual relationships changes. 	<ul style="list-style-type: none"> • Body changes after stroke diminish the sense of self and communication abilities.
	Social participation	<ul style="list-style-type: none"> • Lack of time to socialize or spend time with friends and family. • Inability to engage in previously valued activities. 	<ul style="list-style-type: none"> • Positive impact of higher levels of participation.
Social isolation	<ul style="list-style-type: none"> • Restriction of social activities. • Sense of physical and emotional isolation and absence of social contact. • Fear of social interaction and lack of opportunities to pursue their own interests. • Lack of support of family and friends increased feelings of social isolation. • Increase of social skills, contacts, and new friendships. 		
Positive consequences of care			
Structural adaptation	Problem-solving based coping	<ul style="list-style-type: none"> • Acceptance of a new reality, establish routines, and look for normality in care. 	<ul style="list-style-type: none"> • Acceptance of a new reality, moving the focus from themselves to others.
	Centrality of caregiving role	<ul style="list-style-type: none"> • Intensive and unfamiliar nature of the caregiving role. • Sleep deprivation, fatigue, and lack of time to socialize. 	
	Learning processes	<ul style="list-style-type: none"> • Triggered by unpreparedness, worry, stress, and needs of information and knowledge about the caregiving role, support services, and stroke. 	<ul style="list-style-type: none"> • Learn to use assistance devices after stroke.
	Changes on the daily life activities	<ul style="list-style-type: none"> • Loss of freedom and independence, daily life activities became survivor and home-centered. 	<ul style="list-style-type: none"> • Lack of physical dexterity and independence to manage Activities of Daily Living.
	Financial stress	<ul style="list-style-type: none"> • Loss of family income loss of retirement savings, medical expenses, and lack of adequate insurance added instability and pressure. 	<ul style="list-style-type: none"> • Loss of family income.
	Psychological status of stroke survivors	<ul style="list-style-type: none"> • Mood or personality changes of stroke survivors bring feelings of overwhelm and unappreciation. 	
	Physical health status	<ul style="list-style-type: none"> • New or exacerbated health problems. 	<ul style="list-style-type: none"> • New health problems after stroke.

social benefits, organization and coordination of complex care needs, accessibility support (e.g., transportation and ramps), and grocery shopping, housecleaning, and other errands. Also, social support contributed for facilitating communication by teaching how to use technologies, and promoting the provision of emotional support by having someone available to “openly talk about their deepest fears.”

Despite the importance given to social support, caregivers reported that both formal and informal networks seem to be often scarce in their lives. The studies point

out the barriers to access to support, such as the provision of incorrect information concerning social welfare benefits, the inability of caregivers to ask for support, and the lack of general practitioners’ recognition concerning the impact of the caring role.^{28–31} Also, some caregivers reported feeling misunderstood and unsupported by friends and family, which for some worsened over time.^{22,25,31}

After stroke, caregivers and survivors had to adapt to changes in social roles, namely employment status changes (e.g., retirement, unemployment, sick leave)^{11,22,23,29–31}

and family roles alterations (e.g., assuming the role of a mother or a friend rather than a partner), in some cases leading to role conflicts.^{23,26,28–30,33} In addition to changes in occupational and family roles, there also seem to be changes in relationships, not only between caregivers and survivors but also within the wider family and friends.^{11,22,23,26,28–31,33} Post-stroke communication difficulties, as well as alterations in social and family activities and dynamics, contributed to relationship changes, leading to a lack of understanding and negative emotions such as guilt, frustration, and anger.^{23,28,31}

Furthermore, social participation also emerged as a constituent factor of the adaptive processes of survivors and caregivers.^{11,22,27,31} Although participants stressed the importance of socializing and maintaining their previous social valued activities (e.g., taking vacations, visiting restaurants, going on walks), they reinforced the need to give up on these activities because of their incapacities or overload with daily care.

At the same time, some studies showed that informal care could promote social isolation.^{23,28,29,31} It means that the caregiving role may result in home confinement, loss of a busy and varied social life, free time deprivation, inability to socialize, and loss or resignation of their employment.^{35,36} One of these studies also reinforced that the lack of support from family and friends increased feelings of social isolation across the different stages of care trajectory.³¹

There were studies that highlighted positive consequences on emotional and social dimensions of informal caregivers' lives.^{23,28,33} These caregivers reported closely united partnerships with the stroke survivor, growth and self-improvement, and the development of feelings of belonging and well-being. Additionally, they reported that adapting to care contributed to the increase of social skills, contacts and some referred to new friendships that had been made through their partner's participation in support groups or meetings with other families.

Structural adaptation

The results showed that informal caregivers and stroke survivors need to adapt to a new reconfiguration on practical and daily life issues (Table 3). Most studies showed that problem-solving-based coping strategies were mobilized by survivors and informal caregivers to overcome structural difficulties, namely acceptance of a new reality, establishing routines, looking for normality in caring, moving the focus from themselves to others, and drew on past experiences.^{22,23,25,26,30–32}

Moreover, studies' findings pointed out the centrality of the caregiving role as part of the adaptation processes of informal caregivers.^{23,28–30,33} It was reported that the intensive and unfamiliar nature of this role seems to have consequences on the well-being and social participation of caregivers. One of the studies showed that the centrality that this role occupies in the lives of caregivers promote sleep deprivation, fatigue, and lack of time to socialize or spend time with friends and family.²²

The learning processes of informal caregivers are triggered by feelings of unpreparedness, constant worry, and stress, and by the need to seek information and knowledge regarding the caregiving role, support services, and stroke.^{22,25,26,28–31,33} One study reinforced that survivors need time to learn to use assistance devices after stroke.³⁰

Becoming an informal caregiver seems to foster changes in daily life activities. The loss of freedom and independence was identified by caregivers as a difficulty, with consequences on the ability to do activities spontaneously. Additionally, the daily life activities became survivor and home-centered (e.g., caring for specific tasks, housework, gardening, finance management), demanding that many of them also change their employment status (e.g., retirement, unemployment, sick leave).^{11,23,25,29,31,32} Two studies also reported changes in the Activities of Daily Living of stroke survivors, namely because of the lack of physical dexterity and independence.^{11,32}

Furthermore, some studies reported that informal caregivers and survivors faced financial stress during the adaptation to stroke and caregiving.^{22,23,31,32} The loss of income of stroke survivors and caregivers, the loss of retirement savings, the medical expenses, and the lack of adequate insurance added instability and pressure to the adaptation processes of both.

Moreover, some studies reinforced that the physical health status of caregivers and survivors affected their adaptation processes, namely their comorbidities (urinary, musculoskeletal, skin, cardiovascular, infectious, and gastrointestinal conditions).^{22,24,31,34}

Finally, two studies evidence that informal caregivers also need to adapt to the psychological status of stroke survivors.^{22,31} They reported that mood or personality changes of stroke survivors bring feelings of overwhelm and unappreciation and require new learning skills and coping strategies.

Discussion

This work showed that adaptation to stroke is a complex and multidimensional process that occurred at individual and social levels. Previous literature also emphasized the

complexity of stroke recovery and the adaptation to caregiving roles, highlighting the need for a multidisciplinary approach.³⁷ The circularity and dependence of the psychosocial and structural dimensions, evidence that research and interventions must take place in a non-sectorial, but holistic way, sensitive to the different dimensions and factors of the adaptive processes.

Psychosocial adaptation

The presented findings call attention to the need to identify short and long-term emotional distress, as well as the main determinants and critical stages, to strategically prevent the development of chronic psychiatric conditions. Therefore, interventions should focus on the prevention of the harmful effects of emotional distress, namely the risk of morbidity and the decrease of the QoL of both.³⁸ Also, the centrality of emotion-based coping in the studies, reinforces the need to develop post-stroke long-term educative programs that improve the use of effective and healthy coping strategies to reduce the stroke and care burden.³⁹

This review shows that sleep is not an explored factor, with just one study referring to the sleep disturbances of caregivers as a constituent of the post-stroke adaptation process. Considering the importance of healthy sleep habits on QoL and general well-being,⁴⁰ is crucial to define further Health Education strategies, namely regarding sleep hygiene promotion and governmental policies (e.g., informal caregivers rest rights) to minimize possible negative impacts at short and long-term.

Some studies suggest that employment status may be an important predictor of QoL,⁴¹ the impact of the changes on professional's roles needs to be deeply understood, and return to work should be planned and supported after the recovery period by post-stroke services (e.g., rehabilitation care services).⁴¹ Also, the family roles alterations and consequent tensions that survivors and caregivers need to adapt (e.g., assuming the mother role instead of a wife),⁴² call for the development of strategies that assist dyads to deal with disrupting negative communication cycles, strengthening empathy and collaboration, and achieving a balance so that each person's needs are met.⁴³

This study emphasizes the centrality of formal and informal support for adaptation. Considering its impact on citizens' well-being, general health, and QoL,⁴⁴ social, education, and public health agendas must consider and discuss the promotion of social participation and the reduction of social isolation. In addition to

strengthening informal networks (e.g., family members and close friends), namely through peer support,⁴⁵ community initiatives should promote social engagement after stroke,^{35,46} as well as training of social skills.⁴⁷ Simultaneously, it will also be important to identify risk factors to prevent the exacerbation of feelings of isolation and promote social inclusion.

Although most of the literature tends to focus on the negative experiences of caregiving, some studies have explored the positive dimensions of this role. This review also represents a contribution in this direction by showing that some caregivers identified positive experiences of caregiving influencing their adaptation.⁴⁸ Some sources of satisfaction, especially related to altruistic feelings and the improvement of social skills, were mobilized to support the idea that stressful situations may have a positive impact on caregivers' experiences. Thus, this field would benefit from the study of associated factors, especially through longitudinal studies to track changes and positive influences on caregiving.

Structural adaptation

Post-stroke period requires strategies to actively alleviate the stressful practical, and usually daily-life circumstances, with emphasis on coping. Previous studies often highlight the importance of coping in adaptation, arguing that problem-solving therapy may reduce dependence on primary, psychiatric, and institutional care, with beneficial effects on the individual and social burden and QoL.⁴⁹

This review reveals that social and educational policies and practices must pay special attention to the possibility of social isolation and psychological burden caused by the intensive nature of informal caregiving. As previously reported, alleviate the fatigue,⁵⁰ and strength the formal and informal support⁵¹ should be priorities for health and social systems.

The learning processes were intrinsically related to the caregiving role and its new demands and tasks. Health education policies and strategies directed to caregivers in long-term care can represent useful support tools support to promote a positive adaptation, especially due to the effects on the management of feelings of unpreparedness and on the acquisition of practical knowledge related to stroke care.³⁶ Despite the role of education in adapting to stroke and informal care, namely regarding the management of information needs,³⁹ there is a lack of clear conceptualizations and understanding of this dimension on the adaptive processes. In fact, knowledge on the specificities of the learning process after stroke, as well as their impact on adaptation and the factors that influence them is

lacking. Thus, to facilitate survivors' and informal caregivers' adaptation, post-stroke care will benefit from further research in the field of Educational Sciences. Studies with a specific focus on the learning process will help to define major educational needs and the main enablers and barriers.

The literature is consistent on the existence of changes in daily life activities after stroke,³⁵ converging with this study's results. Educational support that provides skills for managing the new daily life demands, that facilitate the learning of new tasks, and alleviates the associated burden, could represent an essential tool for an effective and positive adaptation. Frequently, the daily life changes after stroke have implications for the economic situations of families, namely because some individuals must leave their jobs, while health expenses increase.⁵² Thus, the adaptation to this new reality must be supported by well-design social policies and community strategies that consider the financial needs of families after a stroke, especially for people of working age.⁵²

Finally, this review showed the impact of the psychological status of survivors on caregivers' adaptation and the effect of survivors' and caregivers' physical comorbidities on the adaptation of both. As previously reported, survivors experience emotional changes, especially triggered by post-stroke depression⁵³ and/or post-traumatic stress disorder,⁵⁴ which has an impact on caregivers' well-being. Also, previous studies found that the physical functioning of survivors and caregivers greatly impacts the QoL of these individuals.⁵⁵ Thus, post-stroke care should promote the individual physical and psychological well-being being aware of the interdependence of dyads.

Limitations

The lack of clear and robust conceptual frameworks, as well as the use of interchangeable definitions regarding the adaptation processes jeopardizes comparisons and conclusions. Furthermore, studies that have explored the educational dimensions of adaptation to stroke and care were rare, which difficult solid conclusions and further strategies for the field of Health Education. However, to capture diverse studies and be suitable for the goals of this scoping review, the databases, the search strategy, and the inclusion criteria were carefully structured, sustained, and discussed.

Concerning the study's designs, the literature seems to be mostly constituted by cross-sectional designs. However, the development of longitudinal studies that include the assessment of adaptation throughout time can represent a useful tool for a better understanding of

the predictors of multi-dimensional adaptation outcomes. It is also clear the scarcity of studies that use quantitative methods and, especially, mixed methods designs. Given the complexity and diversity of experiences in the field of informal care and post-stroke recovery,⁵⁶ as well as the lack of consistent results, it is essential to develop studies that allow a deeper understanding of the adaptation after stroke. Such will contribute to promote advanced knowledge and practice in the post-stroke adaptation field.

The wide range of publication dates can also be seen as a limitation since studies with more than 20 years of age were included. However, since the main purpose of this study was to scope the body of literature, identify knowledge gaps, clarify concepts, and investigate the methodologies used, the inclusion of all studies within the topic under study was the most suitable strategy. Nevertheless, this result calls to attention for the lack of investment in studies in this field in the last years.

The results also showed a scarcity of diversity in the countries of origin of the studies carried out. This poor variability and restrictive cultural and ethnic sensitivity may influence the results, hindering the real understanding of the adaptive processes, and, consequently, the development of inclusive policies and practices suitable for different populations. Thus, the investment in cross-country/cultural studies in the field of informal care and stroke survivors' adaptation should be considered.⁵⁷

Since informal caregiving is most prevalent in groups of elderly people, among middle-aged women and often with a spousal relationship with the care recipient,⁵⁸ is not surprising that the studies included in this review are mostly carried out with female caregivers. However, this disparity can contribute to neglecting some specificities of the adaptation processes of male caregivers, female survivors, and young individuals in studies and interventions.⁵⁹⁻⁶¹ This suggests that research and practices should be aware and inclusive of different and diverse groups of caregivers and survivors, promoting intersectionality research and intervention, and combating gender and ageism stereotypes.

Translation to Health Education Practice

This scoping review is particularly relevant for Certified Health Education Specialists and Masters Certified Health Education Specialists. In particular, this work informs the first, second, and fifth areas of responsibility (I: Assessment of Needs and Capacity; II: Planning; V: Advocacy).⁶² The conduction of a scoping review on an understudy Health

Education topic is aligned with the first area of responsibility, since it allows the identification of knowledge gaps and inform potential further research and intervention strategies (see competency 1.2. Obtain primary data, secondary data, and other evidence-informed sources; and sub-competencies 1.2.3. and 1.2.6.). Additionally, this work was designed to improve the evidence-based recommendations in the field of post-stroke care (see sub-competency 1.4.4.), by addressing factors that may influence the implementation of Health Education policies and practices (see sub-competency 2.4.3.).

Specifically, the findings of this work emphasize that Health Educators and Researchers need to focus on the emotional distress caused by stroke and care, especially considering the role of coping strategies to manage the stress and burden of the adaptive processes (see sub-competency 5.1.1. and 5.1.2.). The centrality of the social aspects of survivors' and caregivers' life stands out the importance of tailored and long-term social support networks and services, directly to individuals and their respective families, promoting social inclusion and participation (see competencies 1.4. Synthesize assessment findings to inform the planning process, 2.4. Develop plans and materials for implementation and evaluation; and sub-competencies 1.4.4., 2.4.3., and 5.1.2.). Additionally, it was highlighted the importance of helping survivors and caregivers to strengthen effective adaptive strategies, while increasing their abilities to balance the new demands with individual well-being (see sub-competency 5.1.2.). Also, long-term educational strategies may help to alleviate feelings of unpreparedness, facilitate the search for information, and promote the acquisition of practical knowledge related to stroke care (see competencies 1.4. Synthesize assessment findings to inform the planning process, 2.4. Develop plans and materials for implementation and evaluation; and sub-competencies 1.4.4., 2.4.3. and 5.1.2.).

Lastly, this work is also linked to competency 1.3 (Analyze the data to determine the health of the priority population(s) and the factors that influence health) by identifying the need for research, policies, and interventions that explore the main dynamics and stages of the adaptation processes, as well as their associated factors (e.g., social, cultural, educational, and economic factors), enabling a clear conceptualization and, consequently, the development of targeted and effective strategies (see sub-competency 1.3.3.).

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ORCID

Ana Moura  <http://orcid.org/0000-0003-4587-6797>

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