

# A Scoping Review on Coping Strategies and Quality of Life of Stroke Caregivers: Often Underestimated Variables in Stroke Recovery Process?

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**Abstract:** The purpose of the present study was to review all available work published within the last decade focusing on coping strategies in stroke caregivers and their impact on quality of Life (QoL) and psycho-emotional status. A literature search of two databases (MEDLINE, Scopus) was conducted to identify all relevant full-text English studies published between 2013–2023. Sixteen articles were traced and were finally included. Cognitive and behavioral coping strategies were beneficial for stroke caregivers' and survivors' QoL. The level of mutuality in the caregiver-survivor relationship was associated with the impact of depressive symptoms on caregivers' QoL and the protective effect of mutuality on survivors' QoL over time. The level and quality of social support were positively associated with QoL for stroke caregivers and survivors. Caregivers' preparedness was a moderator for the impact of depression on both caregivers' and survivors' QoL. High levels of spirituality had a significant role in ameliorating the negative impact of depressive symptoms on the psychological and physical QoL of stroke caregivers and survivors. In conclusion, the study of coping strategies can be used as a psychological reserve in the process of stroke rehabilitation and actively contribute to improving the QoL of both caregivers and stroke survivors.

**Keywords:** stroke; caregivers; coping strategies; quality of life; psycho-emotional status



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## 1. Introduction

Stroke has risen to the second leading cause of death among adults and one of the leading causes worldwide [1]. It is indicative that every 40 s one person has a stroke in the USA. Post-stroke consequences do not include only patients' deficits but also the associated patients' need for constant help. The latter is almost always provided by the patient's family members, and especially by the wife [2]. These unseen heroes are characterized as informal caregivers [3]. Informal caregivers take on many responsibilities, which range between the many roles they are called upon to play in patients' lives. This fact makes their work even more difficult [4]. These individuals are an invaluable and inexhaustible source of care for stroke patients, as they play an active role both in the acute phase and during rehabilitation, therefore constituting an important -but still missing- variable for models that try to predict stroke prognosis based on different biomarkers.

Depending on the stage of the illness, family caregivers have different needs that are categorized into five stages. These stages are event/diagnosis, stabilization, preparation, implementation, and adaptation [5]. The first two stages refer to the acute phase of the stroke, the third stage occurs during inpatient rehabilitation and the last two stages occur during the patient's reintegration into the community. At each stage, there is a need for specialized knowledge that caregivers must receive and the corresponding support that must be provided to them. For example, in the acute phase, caregivers require information about the disease, its progression and treatment [6]. In fact, caregivers involuntarily experience time pressure. In this "state of emergency" they experience, health professionals' honesty and to-the-point answers about the patient's condition and possible changes are necessary information to be provided to them [6–8]. Otherwise, the caregiver may develop feelings of uncertainty and anxiety [5]. During the post-discharge transition, informal caregivers are faced with new issues related to the disease and its symptoms, such as patient safety and emotional response, equipment needed at home treatment, the level of care to be provided, medication management, etc. All the above are a source of stress and the lack of knowledge and information about them increases these negative caregivers' feelings [6].

All this disruption inevitably affects the quality of life (QoL) of caregivers as well. People who have survived a stroke, have the hard path of recovery to go through. The remnants of the stroke are evident in many different areas of their functionality, related to physical deficits as well as cognitive impairments and emotional disturbances [9]. The above issues will likely affect the person's daily life and social activities but they will inevitably affect the lives of their caregivers as well [10], thus often leading to a vicious cycle.

Coping strategies refer to psychological and behavioural efforts used to manage the specific external or internal person's demands [11] and they are designed to modify the stressful circumstances and regulate the emotional distress connected to the situation [12,13]. Positive coping strategies have been shown to decrease distress and depression while improving vitality and mental well-being [13,14]. In contrast, passive avoidant coping strategies can cause negative emotional and psychological outcomes among stroke caregivers [13].

Caregivers who receive adequate social support report less perceived stress and better mental well-being, as well as a greater zest for life than those without the corresponding benefits [13]. Past research has shown that older age and female gender were negatively associated with QoL [15–17], although the gender issue tends to decline [13], and chronic illness was associated with impaired QoL [18]. In contrast, educational level was associated with better caregiver physical [13,19] and emotional health [20]. Another factor that affects the emotional and social functioning of caregivers and their mental and physical health is income [21].

The needs of caregivers are different at each stage of the disease, and the timelessness of this knowledge is already recorded [5,6]. There could be emotional differences between caregivers depending on the duration of the illness. Unfortunately, only specific periods have been studied in the literature, and those individually [6]. Considering the role of caregivers in the prognosis of stroke patients both short-term and long-term, we aimed to comprehensively review coping strategies and QoL in stroke patients' caregivers both in the acute and chronic stroke phase. The review will consider the broader context in which stroke caregivers operate, including the healthcare systems, community resources, cultural factors, and social support networks available to them. It will explore how these contextual factors influence coping strategies and the overall quality of life among stroke caregivers. More specifically, with the present research we aim to analyze the components that can influence the formulation of coping strategies based on the characteristics of caregivers, patients and the disease itself, as the assessment and analysis of psycho-emotional changes is a multifactorial process for health professionals

## 2. Methods

This scoping review used the 22-item Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR). Our study's methods were a priori designed [22].

The last literature search was conducted on 9 February 2023.

### 2.1. Research Strategy

Two investigators (AT and PV) conducted a literature research to trace all relevant studies published on the measures of coping strategies and QoL used by the caregivers of stroke patients. Studies were identified by searching the last 10 years (2013–2023) on MEDLINE and Scopus databases. The search combined the following terms: “stroke” AND “quality of life” AND “coping strategies” AND “caregivers” (Table 1). Any disagreement regarding the screening or the selection process was discussed with a third investigator (KV) until a consensus was reached.

**Table 1.** Employed databases and search strategies.

Database	Search Strategy
Pubmed	“stroke” AND “quality of life” AND “coping strategies” AND “caregivers”
Scopus	TITLE-ABS-KEY (“stroke” AND “quality of life” AND “coping strategies” AND “caregivers”)

### 2.2. Selection Criteria

The search terms were identified as title and abstract. After duplicates had been removed, all articles were evaluated based on title, abstract, and text. Studies that examined the coping strategies and QoL in caregivers of stroke patients were included. The population of interest for this scoping review is stroke caregivers. Stroke caregivers refer to individuals who provide support, assistance, and care to stroke survivors during their recovery process. The term caregivers may include family members, spouses, partners, friends, or other individuals who are actively involved in the care and well-being of stroke survivors. The review will focus on caregivers of stroke survivors across different age groups, genders, cultural backgrounds, and socioeconomic statuses.

Only full-text original articles published in the English language were included. Secondary analyses, reviews, guidelines, notes, errata, letters, meeting summaries, comments, unpublished abstracts, or studies conducted on animals were excluded. There was no restriction on study design or sample characteristics. The main concepts to be explored in this scoping review are coping strategies and quality of life among stroke caregivers.

### 2.3. Data Extraction

The main details of each study were extracted in a predefined data form created in Excel. More specifically, we recorded author, year of publication, type of research, number of caregivers, time since stroke onset, type of the caregiver (formal-informal), characteristics of the participants, psychometric scales/interviews used to assess coping strategies and QoL, and main outcomes of the study related to the aim of the present review.

## 3. Results

### 3.1. Database Searches

From the search of the two databases 113 articles were retrieved in total, while duplicates and irrelevant studies were excluded; hence, a total of 90 articles were selected. After completing the final selection due to eligible criteria, 16 studies were included (Figure 1). These 16 studies that met the inclusion criteria, are presented in detail in Table 2.

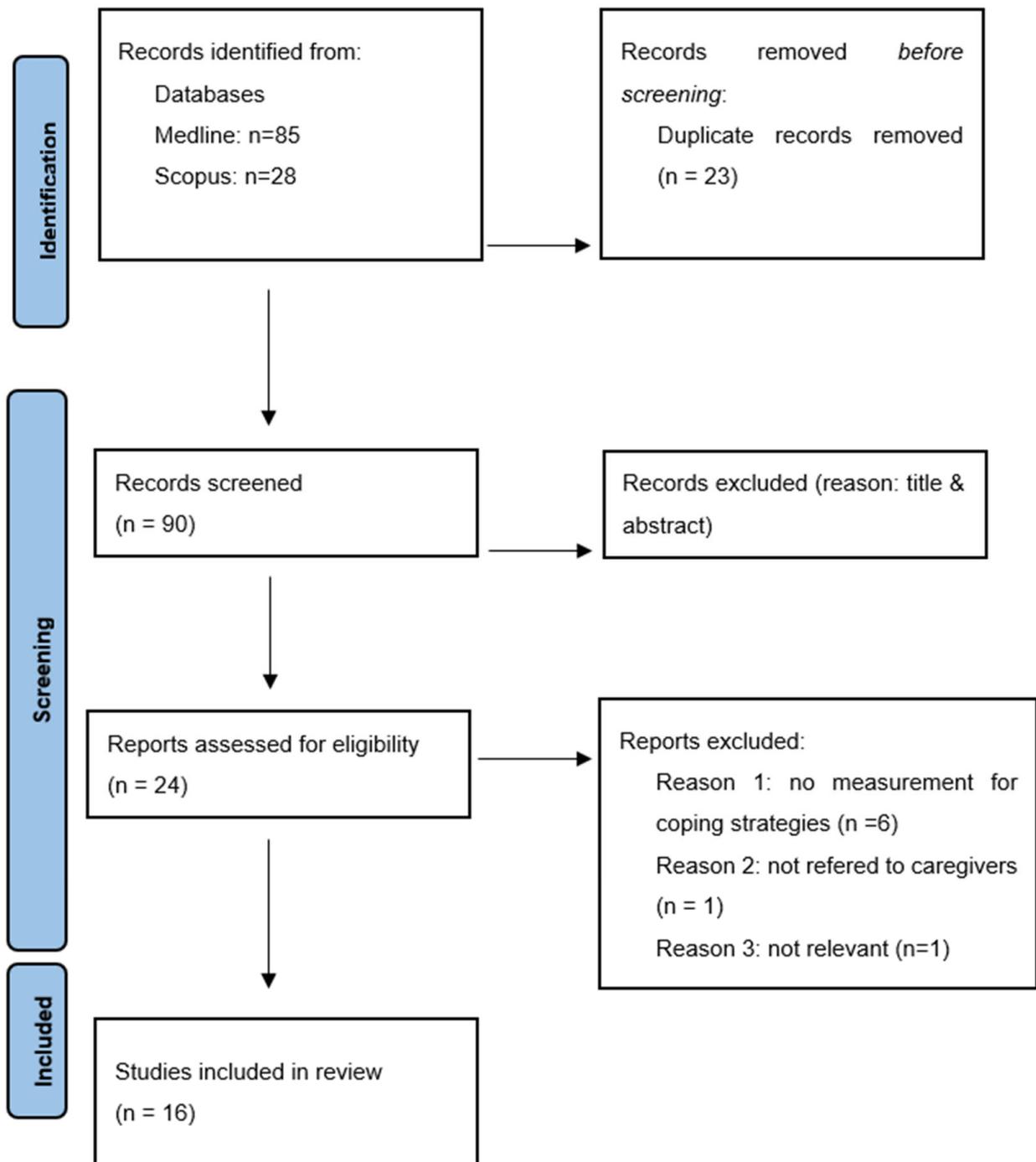


Figure 1. Study flow diagram (PRISMA flowchart).

Table 2. Characteristics of the included studies.

1st Author (Year)	Study Design, Participants (n), Caregivers' Age (Years)	Time Since Stroke Onset	Caregivers' Type	Caregiver's Characteristics	QoL and Psycho-Emotional Status Scales	Coping Strategies Scales	Coping Strategies Identified	Main Findings
1 Yu (2013) [13]	<ul style="list-style-type: none"> <li>• Cross-sectional, 121 survivors-caregiver dyads,</li> <li>• 61.15 ± 0.79</li> </ul>	After discharge at home	Informal (spouse, adult children, siblings, other relatives, friends and sitters)	<ul style="list-style-type: none"> <li>• Care of the stroke survivor for at least 4 weeks,</li> <li>• Adult caregivers</li> </ul>	SF-36	Brief COPE Inventory (BCI), Multidimensional Scale of Perceived Social Support (MSPSS)	Acceptance, active coping, positive reframing and planning	<ul style="list-style-type: none"> <li>• Caregivers scored very low on the social functioning,</li> <li>• No association between perceived social support to and caregivers' health-related QoL.</li> <li>• Problem-focused coping strategies, active coping and planning were positively associated with the mental health of caregivers.</li> <li>• Higher educational level was associated with better health-related QoL.</li> </ul>
2 Alquwez (2021) [23]	<ul style="list-style-type: none"> <li>• Cross-sectional</li> <li>• 123 caregivers,</li> <li>• 44.45 ± 8.14</li> </ul>	Home care	Informal (family members)	<ul style="list-style-type: none"> <li>• Care to a stroke survivor family member,</li> <li>• Not receiving financial compensation for the care</li> </ul>	WHO QOL-BREF, Hospital Anxiety and Depression Scale	Spiritual Coping Strategies scale, Multidimensional Scale of Perceived Social Support	Spiritual coping strategies (attending to mosques, performing Salah, reading and reciting the Qur'an (i.e., holy book), attending Umrah, and trusting Allah (i.e., God)	<ul style="list-style-type: none"> <li>• The QOL of the caregivers can be interpreted as moderate.</li> <li>• The respondents received the highest support from "significant others," then "family," and "friends."</li> <li>• Social support positively influenced the QOL of the respondents.</li> <li>• Religious coping strategies were more frequently used than existential spiritual coping.</li> <li>• The utilization of existential spiritual coping strategies may lead to healthy physical and environmental aspects.</li> </ul>
3 El Masry (2013) [24]	<ul style="list-style-type: none"> <li>• Qualitative,</li> <li>• 20 caregivers</li> </ul>	After discharge at home 3 months prior to the interview, admitted to rehabilitation services	Informal (family members)	<ul style="list-style-type: none"> <li>• Primary unpaid caregiver for someone with stroke for at least 3 months and assisting the stroke survivor with at least one major activity of daily living (ADL)</li> </ul>	N/A	Semi-structured interviews: themes; relationship and support, caregiver factors, stroke survivors, external stressors factors, positive outcomes	Cognitive strategies: seeking, attention diversion, goal setting, solution-focused problem solving	<ul style="list-style-type: none"> <li>• Stroke caregivers underwent a series of psychological, emotional, interpersonal, social, health, and occupational changes because of undertaking this role.</li> <li>• Cognitive and behavioral coping strategies appeared to be beneficial.</li> </ul>

Table 2. Cont.

1st Author (Year)	Study Design, Participants (n), Caregivers' Age (Years)	Time Since Stroke Onset	Caregivers' Type	Caregiver's Characteristics	QoL and Psycho-Emotional Status Scales	Coping Strategies Scales	Coping Strategies Identified	Main Findings
4 Pucciarelli (2022) [25]	<ul style="list-style-type: none"> <li>Longitudinal, 222 stroke survivor-caregiver dyads, 70.8 ± 11.9 (patients), 52.4 ± 13.1 (caregiver)</li> </ul>	3 months to 1 year after discharge from hospital	Primary informal caregiver	<ul style="list-style-type: none"> <li>Living with stroke survivor</li> <li>Inside or outside the family who provided them with most of their informal care</li> </ul>	WHOQOL-BREF (World Health Organization Quality of Life—BREF), Caregiver Burden Inventory, Hospital Anxiety and Depression Scale,	Mutuality scale, Caregiver Preparedness Scale	Preparedness	<ul style="list-style-type: none"> <li>Caregiver preparedness moderates the influence of depression on caregivers' QoL, as well as the effects of depression on the survivors' QoL.</li> <li>A new role for caregiver preparedness as a moderator was determined.</li> </ul>
5 Pucciarelli (2021) [26]	<ul style="list-style-type: none"> <li>Longitudinal, 222 stroke survivor-caregiver dyads 70.8 y ± 11.9 (patients), 52.5 ± 13.1 (caregivers)</li> </ul>	Sub-acute, chronic phase	Informal	<ul style="list-style-type: none"> <li>Inside or outside the family who provided them with most of their informal care</li> </ul>	Hospital Anxiety and Depression Scale, WHOQOL-BREF (World Health Organization Quality of Life—BREF), Caregiver Burden Inventory	Mutuality Scale	mutuality	<ul style="list-style-type: none"> <li>The lower the mutuality is, the greater impact on caregiver physical, psychological, and social QoL is observed. Regarding survivors, mutuality with the caregiver does not seem to have a positive moderating effect on the presence of depressive symptoms but does have an independent protective effect on physical, psychological, and social QoL over time.</li> </ul>
6 Pucciarelli (2020) [27]	<ul style="list-style-type: none"> <li>Quantitative, 223 stroke-survivor-care partner dyads, 70.7 ± 12.03 (patients), 52.33 ± 13.19 (caregivers)</li> </ul>	After discharge at home	Informal	<ul style="list-style-type: none"> <li>Spouses of patients, unpaid, adult children, siblings, other relatives, friends and sitters</li> </ul>	QoL, WHOQOL-BRIEF (World Health Organization Quality of life-BRIEF), Hospital Anxiety and Depression Scale	WH OQoL-SRPB scale	Spirituality	<ul style="list-style-type: none"> <li>The spirituality played a significant role in ameliorating the association between depressive symptoms and poor QoL for both survivor and care partner.</li> <li>High levels of spirituality mitigated the negative impact of the care partner's depressive symptoms (psychological QoL of survivor and care partner).</li> <li>No effect of spirituality on QoL changes.</li> </ul>

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1st Author (Year)	Study Design, Participants (n), Caregivers' Age (Years)	Time Since Stroke Onset	Caregivers' Type	Caregiver's Characteristics	QoL and Psycho-Emotional Status Scales	Coping Strategies Scales	Coping Strategies Identified	Main Findings
7 Dewilde (2019) [28]	<ul style="list-style-type: none"> <li>Observational retrospective, 539 patients</li> </ul>	3–36 months after hospital discharge	N/A	N/A	EQ-5D-3L	Dependency on caregivers scale, Brandstädter and Renner Coping questionnaire	Assimilative coping (tenacious goal pursuit-TGP), accommodative (flexible goal adjustment-FGA)	<ul style="list-style-type: none"> <li>No strong relationship between coping style (used by survivors) and dependency on carers.</li> <li>Dependency on caregivers influences QoL.</li> <li>Positive effect of coping varies by coping strategy (FGA is associated with increases in utility, TGA shows no significant impact).</li> </ul>
8 Dharma (2018) [29]	<ul style="list-style-type: none"> <li>Experimental, 80 post-stroke patients and their families,</li> <li>Intervention group: 40 participants</li> <li>Control group: 40 participants</li> </ul>	Post-discharge from hospital of less than one month (currently undergoing treatment at home)	Informal	<ul style="list-style-type: none"> <li>Dominant role in caring for or assisting the patient at home</li> <li>Age: &lt;60 years</li> </ul>	Stroke-specific quality of life (SSQoL)	N/A	Adaptive coping strategies	<ul style="list-style-type: none"> <li>Significant difference in functional capacity and QoL between the two groups and between pre-test and 6 months after intervention.</li> <li>QoL of the intervention group in 6 months after intervention was significantly better than that of the control group.</li> <li>CEP-BAM effectively improved functional capacity after stroke.</li> <li>The increase in functional capacity after stroke was a positive effect on adaptation exercises or body movement.</li> </ul>

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1st Author (Year)	Study Design, Participants (n), Caregivers' Age (Years)	Time Since Stroke Onset	Caregivers' Type	Caregiver's Characteristics	QoL and Psycho-Emotional Status Scales	Coping Strategies Scales	Coping Strategies Identified	Main Findings
9 Anderson (2022) [30]	<ul style="list-style-type: none"> <li>Qualitative,</li> <li>18 participants</li> <li>53.3 ± 14.7</li> </ul>	0.5–6.5 years after stroke	Informal	<ul style="list-style-type: none"> <li>“Romantic partners”, Couples</li> </ul>	N/A	<ul style="list-style-type: none"> <li>Qualitative data through semi-structured post-intervention feedback interviews.</li> <li>Participants completed post-intervention surveys followed by interviews including expansion of survey answers and open-ended interview questions.</li> </ul>	Resilience	<ul style="list-style-type: none"> <li>Intrapersonal factors (e.g., coping, personality) facilitate resilience.</li> <li>Interpersonal characteristics (e.g., relationship quality and social support) influence the development and expression of resilience, and socio-ecological influences (e.g., accessibility, cultural attitudes) that provide context to this dynamic interaction.</li> <li>Interpersonal and other relational factors are highly relevant to coping with disability and impact resilience: disability, intrapersonal, interpersonal, social, resilience, and QoL/well-being.</li> </ul>
10 Mores (2018) [31]	<ul style="list-style-type: none"> <li>Quantitative/qualitative</li> <li>42 participants,</li> <li>61.7 (range 38–84)</li> </ul>	<ul style="list-style-type: none"> <li>T1 = baseline;</li> <li>T2 = 2 weeks and</li> <li>T3 = 6 months after stroke</li> </ul>	Informal	<ul style="list-style-type: none"> <li>Spouses of the stroke survivor, care time 4.6 years (3 months–22.2 years)</li> </ul>	Oberst Caregiving Burden scale	Bacas Caregiving Outcome Scale	Self-management	<ul style="list-style-type: none"> <li>Self-management approach leads to: establishment of connections with other caregivers, improved self-care, coping skills, awareness and use of community supports and better QoL.</li> </ul>
11 Cecil (2013) [32]	<ul style="list-style-type: none"> <li>Qualitative descriptive,</li> <li>30 participants</li> <li>Females (n = 23): 36–38 years</li> <li>Males (n = 7): 73–84 years</li> </ul>	6 weeks following hospital discharge	Informal	<ul style="list-style-type: none"> <li>Carers of first-time stroke patients who did not have a history of caring</li> </ul>	N/A	Qualitative data were collected through semistructured interviews	Intrinsic factors that help a carer to cope with the new role	<ul style="list-style-type: none"> <li>Extrinsic factors that support the caring scenario and intrinsic factors that help a carer to cope with the new role were identified.</li> <li>Health and Well-being, Gratitude and Faith, Dyadic Relationship and Family support were underlined.</li> </ul>

Table 2. Cont.

1st Author (Year)	Study Design, Participants (n), Caregivers' Age (Years)	Time Since Stroke Onset	Caregivers' Type	Caregiver's Characteristics	QoL and Psycho-Emotional Status Scales	Coping Strategies Scales	Coping Strategies Identified	Main Findings
12 Gholamzadeh (2015) [33]	<ul style="list-style-type: none"> <li>Qualitative,</li> <li>17 participants</li> <li>Mean age: 36.4</li> </ul>	Acute phase of stroke recovery at home	Informal	<ul style="list-style-type: none"> <li>Daughter and daughter in law caregivers, lived in the same house with the survivor</li> </ul>	Focus group discussion (FGD) and individual in-depth interviews	Focus group discussion (FGD) and individual in-depth interviews	<ul style="list-style-type: none"> <li>Several types of emotion-focused coping</li> <li>Religious approach and a combination of positive reappraisal (finding positive meaning through events), seeking emotional and social support, self-controll, and expression of emotions.</li> </ul>	<ul style="list-style-type: none"> <li>Predominantly emotion-oriented coping approach helps to stressful situation adaptation.</li> <li>Problem-oriented coping strategies prepare individuals better to cope with home care needs.</li> </ul>
13 Lopez-Espuela (2018) [34]	<ul style="list-style-type: none"> <li>Qualitative,</li> <li>18 participants</li> </ul>	6 months after discharge	Informal	<ul style="list-style-type: none"> <li>Spouses of survivors</li> <li>5 male spouse and 13 female spouses</li> </ul>	Individual, semi-structured, in-depth interviews	Quality data through semistructured interviews	Identification of coping strategies through critical points from the interviews	<ul style="list-style-type: none"> <li>Transition care approach was identified.</li> </ul>
14 Kruithof (2016) [35]	<ul style="list-style-type: none"> <li>Prospective cohort,</li> <li>183 participants,</li> <li>62.5 ± 10.9</li> </ul>	Within the first week post-stroke	Informal	<ul style="list-style-type: none"> <li>Partners of stroke survivors</li> </ul>	Caregiver Strain Index (CSI), Hospital Anxiety and Depression Scale (HADS)	Utrecht Proactive Coping Competence Scale (UPCC), General Self-efficacy Scale (GSES), Social Support List-Interaction (SSL-12-I)	Proactive coping, self-efficacy, relationship satisfaction and everyday support	<ul style="list-style-type: none"> <li>A substantial part of the stroke partners experiences high levels of burden, anxiety, or depressive symptoms in the sub-acute and the chronic phase post-stroke.</li> <li>The levels of anxiety symptoms were high.</li> <li>The levels of burden and depressive symptoms did not decline over time.</li> </ul>
15 Sadler (2017) [36]	<ul style="list-style-type: none"> <li>Qualitative,</li> <li>5 caregivers</li> </ul>	8–22 months post stroke	Informal	<ul style="list-style-type: none"> <li>Family members</li> </ul>	HRQoL-SF12	Interviews, Brief resilience scale	Qualitative analysis	<ul style="list-style-type: none"> <li>Resilience comprises a range of psychological, social and environmental factors.</li> </ul>

Table 2. Cont.

1st Author (Year)	Study Design, Participants (n), Caregivers' Age (Years)	Time Since Stroke Onset	Caregivers' Type	Caregiver's Characteristics	QoL and Psycho-Emotional Status Scales	Coping Strategies Scales	Coping Strategies Identified	Main Findings
16 Hallam (2014) [37]	<ul style="list-style-type: none"> <li>• Cross-sectional,</li> <li>• 71 participants,</li> <li>• 66.5 ± 11.4</li> </ul>	Mean caring period 9.2 ± 7.1 years post-stroke	informal	<ul style="list-style-type: none"> <li>• Spouses</li> <li>• &gt;50 caring hours/week</li> <li>• 62% of respondents, 32.4% stroke club attenders, 15.5% received additional support from professional carers.</li> </ul>	Adult Carer Quality of Life	The Coping Orientation to Problems Experienced, The Post-Traumatic Growth Inventory, Multidimensional Scale of Social Support, The Rumination Scale	<ul style="list-style-type: none"> <li>• Post-traumatic growth (PTG) determined by (1) event-related factors, (2) environmental factors, (3) personal factors, and (4) cognitive and coping responses.</li> <li>• Cognitively oriented model.</li> <li>• Traumatic experiences are 'seismic events'.</li> </ul>	<ul style="list-style-type: none"> <li>• No association between active coping, acceptance coping, age and PTG.</li> <li>• Avoidance coping was associated with PTG.</li> <li>• Social support was positively associated with PTG.</li> </ul>

### 3.2. Type of Research

The social and cultural contexts of the studies included are enormously variable and add value to the interpretation of the data. The types of research consisted mainly of qualitative studies, while fewer used quantitative measurements.

The superiority of qualitative research is due to the fact that it offers a deeper understanding of the experience of caring [38]. Understanding what can be helpful in this role provides useful knowledge and information that can be transferred to others, who are able to provide care for people after stroke. Interviews are not restricted to specific questions and can highlight issues, such as role and relationship settings, while they offer improved information for education and unmet needs [39]. Open discussion and communication with caregivers strengthen trust and give the opportunity to express the positive aspects of care by focusing on the resources and capabilities of the caregivers themselves. Hence, some limitations of qualitative studies should be mentioned. First, research quality and interpretation of data are mainly dependent on the researcher's skills, which may simultaneously affect subjects' responses. Secondly, the method of the thematic content analysis used by qualitative research may de-emphasize specific issues, as it focuses more on the similarities of opinions than on their differences and a lot of dependent variables are being ignored. Conversely, quantitative research can ease the comparison between different groups to understand similarities and differences on a larger scale. Moreover, it can reveal insights about broader groups of stroke caregivers, while the data are less susceptible to bias. However, when results are based on numerical responses, less knowledge could be gained about the thoughts and motivations of the target group. Thus, the results cannot always represent the actual occurrence and the findings cannot be generalized [40]. Only few longitudinal studies were found. However, this type of research design has the potential to identify changes over time and provide insight into cause-and-effect relationships in carers' experience [41].

### 3.3. Caregivers' Characteristics

The information that was provided about the caregivers varied in terms of the specific demographics that were reported, such as age, gender, race/ethnicity, education level, and socioeconomic status. All the studies of this review included informal caregivers, consisting of family members and friends. This finding can be interpreted by the social context in which the study took place. The caregiving role is described as a demanding task with increased responsibility. The functioning of the role is being conditioned by specific moderators, such as the amount of time spent for caring [13], the energy invested on the role [42], physical and emotional efforts [23,35], sufficient training [33] and cultural expectations [43]. Of note, in the study of Yu [13], caregivers reported low levels of social functioning, due to restrictions derived from caring, estimating an average daily time spent at 8 h. The time and energy spent resulted in reduced individual freedom and encumbrance on caregivers' lives. A similar finding was indicated in the research of Alquwez [23], i.e., a caregiver is possible to experience the same levels of depression and anxiety as those felt by the patient, because of physical and emotional burden. In the same line Gholamzadeh et al. [33] highlight the need of sufficient training towards to challenges frequently reported by family caregivers, such as lack of home care services and paucity of financial support. Cultural expectations about caring are related to religious context as a part of their culture. Lopez et al. [34] attempted to shed light on the negative psychological experiences of the spouses who care for a partner after a stroke. The interpretation lies in the management of bereavement after the loss of normality around daily functioning, the inability to plan a life, the uncertainty surrounding the stroke and its consequences, as well as the increasing dependence of patients even in simple activities [34]. Finally, it was also found that through therapeutic approaches and appropriate interventions, some factors can contribute to the management of the negative psychological consequences of

care and enhance the quality of life, such as psychological empowerment, coping strategies and sources of social support [35].

### 3.4. *Time since Stroke Onset and Duration of Care for Stroke Survivors*

Time since stroke and the duration of caregiving are important factors for caregivers' needs and their QoL. Mores et al. [31] found that the mean time since stroke onset was 4.4 years, and the mean duration of caregiving was 3.6 years. Similar durations were also reported in most of the reviewed studies; 1.5 years since stroke with 19.2 months mean duration of caregiving [37], 6.5 years since stroke with 5.2 years mean duration of caregiving [32], 13.5 months since stroke with 11.3 months mean duration of caregiving [29], 1.2 years since stroke with 1 year mean duration of caregiving [24]. Yu et al. [13] reported that duration of caregiving was not significantly associated with the health-related QoL of caregivers. The studies in this review are usually conducted when the hospital or rehabilitation clinic discharge process begins and during the first period in the chronic phase of stroke. A key element to caring is when and how the transition to care occurs [44]. The way in which the role of caring is adopted determines the level of awareness and involvement in this role. Many studies noted that the needs of caregivers change according to the stage of assuming the role, but also according to the time invested in the care process [45,46]. Naturally caregivers are not prepared and trained to meet the new demands and this leads to disinvestment and feelings of helplessness. Greenwood et al. [39] suggested to avoid assuming that the experience of caregivers from different time frames could be similar and group them together. The time factor from the stroke and the duration of care are regulatory factors in meeting the needs of caregivers.

### 3.5. *Outcomes on Quality of Life*

The outcomes related to QoL varied among the studies. Some studies found that caregiver burden and depression had a negative impact on the QoL of both caregivers and stroke survivors [25,34]. Other studies found that caregiver preparedness and social support could improve the QoL of both caregivers and stroke survivors [13,23]. Additionally, some studies found that the QoL of caregivers and stroke survivors could be affected by factors such as caregiving intensity, disruption in the couple's life, and loneliness of caregiving. Overall, the results suggest that QoL is a complex construct that can be influenced by a variety of factors, including caregiver characteristics, stroke survivor characteristics, and the nature of the caregiving relationship. In general, caregivers reported feeling overwhelmed and unprepared for the caregiving role, high levels of emotional distress, including anxiety and depression, high levels of burden and negative impacts on their physical and emotional health, a range of emotions, including anxiety, depression, and grief.

### 3.6. *Outcomes on Coping Strategies*

Cognitive and behavioral coping strategies were found to be beneficial for stroke caregivers' and survivors' QoL. Hallam & Morris [37] in their study, investigated the relationship between coping styles and post-traumatic growth, as well as the factors identified by two models of post-traumatic growth provided by Schaefer and Moos [47] and Tedeschi and Calhoun [48]. The study found that coping styles were not significant predictors of post-traumatic growth, but deliberate rumination and intrusive rumination were associated with post-traumatic growth. Yu et al. [13] highlighted the most frequent coping strategies employed by caregivers were acceptance, active coping, positive reframing, and planning. In addition, problem-focused coping strategies, active coping, and planning were positively associated with caregivers' mental health. Overall, these findings suggest that stroke caregivers in China face significant challenges to their health-related QoL, and interventions that target these challenges, such as providing more social support and promoting positive coping strategies, may be helpful. Spiritual coping was found to have a positive influence on mental health and QoL [23]. The results of this research suggest that cultural factors, coping strategies, accessibility of support systems, and the prevalence of mental health

problems among stroke survivors may all contribute to the high levels of depression and anxiety observed in caregivers. Finally, Yu et al. [13] underlined that the most frequent coping strategies employed by caregivers were acceptance, active coping, positive reframing, and planning.

### 3.6.1. Mutuality

The level of mutuality in the caregiver-survivor relationship was found to be associated with the impact of depressive symptoms on caregiver QoL and the protective effect of mutuality on survivor QoL over time. Pucciarelli et al. [26] found that mutuality played a significant moderating role in the association between depression scores and QoL scores for physical, psychological, and social dimensions, but not for environmental QoL dimensions. Higher survivor mutuality was significantly associated with higher survivor psychological and social QoL at baseline, while higher caregiver mutuality significantly moderated the association between caregiver depressive symptoms and caregiver physical, psychological, and social QoL at baseline. Although there was no significant moderating role of mutuality on change in QoL over time for either survivor or caregiver, higher survivor mutuality was significantly associated with greater improvement in survivor physical QoL over time, while higher caregiver mutuality was significantly associated with less improvement in caregiver physical QoL over time.

### 3.6.2. Social Support

The level and quality of social support from family, friends, and significant others were found to be positively associated with QoL for stroke caregivers and survivors. Hallam & Morris [37] found that social support was positively associated with post-traumatic growth and explained post-traumatic growth in each of the regression analyses, with evidence for the proposal that social support affects post-traumatic growth indirectly through deliberate rumination. In addition, Kruithof et al. [35] identified several partner and patient variables that explained partner outcomes, including partners' psychosocial factors, such as satisfaction with their relationship, proactive coping, self-efficacy, and everyday social support. Yu et al. [13] concluded that stroke caregivers' health-related QoL scores were lower than those of the Chinese population, except for role emotional scores. They also reported insufficient perceived social support, especially from friends and other members of their social network. These findings suggest that stroke caregivers in China face significant challenges to their health-related QoL, and interventions that target these challenges, such as providing more social support and promoting positive coping strategies, may be helpful. In a more recent study [23], social support from significant others, family, and friends was rated as high, with excellent social support from friends being linked to low depression and anxiety scores. The above study emphasizes the importance of social support in maintaining good mental health and suggests that interventions targeting depression and anxiety should be integrated into stroke rehabilitation programs.

### 3.6.3. Preparedness

Caregiver preparedness was identified as a moderator that can influence the impact of depression on both caregiver and survivor QoL. The study of Pucciarelli et al. [25] investigated the moderating role of caregiver preparedness on the association between depression and QoL for stroke survivors and their caregivers. Higher levels of caregiver preparedness were protective and buffered the influence of survivor depression on survivor psychological and environmental QoL at baseline. Interestingly, caregiver preparedness did not significantly moderate the association between caregiver depression and caregiver QoL in each dimension at baseline. In terms of changes in QoL, caregiver preparedness significantly moderated the association between survivor depression and survivor social QoL over time. No significant changes were observed for survivor physical, psychological, and social QoL over time. On the other hand, caregiver preparedness significantly moderated the association between caregiver depression and caregiver physical and environmental

QoL over time. No significant changes were observed in caregiver psychological and social QoL over time. Overall, the findings suggest that higher levels of caregiver preparedness are protective against the negative effects of depression on QoL for stroke survivors and their caregivers. However, the effects of preparedness vary depending on the dimension of QoL and whether it is at baseline or over time.

#### 3.6.4. Resilience

Resilience was found to comprise a range of psychological, social, and environmental factors that can facilitate coping and adaptation to the challenges of stroke caregiving. Sadler et al. [36] in their attempt to capture changes in anxiety and depression scores, found a marginal increase in mean resilience scores from baseline to follow-up, with scores varying within the group. There was no change in mean activity levels or depression scores, but a marginal increase in mean physical-health QoL and mental-health QoL scores, and a slight increase in mean anxiety scores. Missing data and memory problems among some participants limited the ability to draw firm conclusions.

#### 3.6.5. Spirituality

High levels of spirituality were reported to have a significant role in ameliorating the negative impact of depressive symptoms on the psychological and physical QoL of both stroke caregivers and survivors. Pucciarelli et al. [27] examined the moderating role of spirituality on the association between depressive symptoms and QoL. Survivor spirituality significantly moderated the association between care partner depressive symptoms and care partner physical QoL at baseline, with the association being weaker in care partners caring for survivors with high levels of spirituality. Additionally, survivor spirituality moderated the association between care partner depressive symptoms and survivor psychological QoL at baseline, with survivors having higher levels of psychological QoL when they had high levels of spirituality. Care partner spirituality was also significantly positively associated with baseline care partner QoL. However, there were no significant moderating effects on change in QoL.

### 4. Discussion

The present review sought to investigate coping strategies and QoL in stroke caregivers both during the acute/subacute and chronic stroke phase. Despite methodological differences between the included studies, it appears that coping strategies not only play an important key role for caregivers' QoL and psycho-emotional status but also represent an important factor for stroke survivors' QoL as well.

Considering the role of caregivers in stroke survivors' prognosis, we also tried to identify the theoretical framework for the development of therapeutic or educational interventions for successful coping strategies that can directly and indirectly contribute to caregivers' and stroke survivors' QoL, respectively. Only two structured intervention programs were identified [29,31]. The first one described a caregiver empowerment program (based on an adaptation model) to apply psychological adaptive coping strategies, while the second one evaluates the impact of the Family Informal Caregiver Stroke Self-Management program on burden and life changes. The operation of these programs was based on the belief that the caregiver should participate in the support network of the patients, but for which he is not properly prepared and trained. The aim of the intervention programs is therefore to strengthen the open dialogue, the building of trust, the facilitation of communication and the search for effective coping strategies [49,50]. In another study [36], an intervention promoting resilience to improve psychosocial outcomes after stroke was discussed, which was guided by the revised UK Medical Research Council framework [51]. It describes a novel intervention conceptually grounded from the literature and empirical research consisting of stroke survivors, caregivers, and health professionals. Alquwez [23] summarized the benefits of social support, which is not provided by structured intervention programs, but from family members and friends. Previous studies have

also highlighted this superiority of significant others in the psychosocial health of stroke survivors and caregivers [52–54]. The main source of support for the caregivers themselves is the people close to them, who provide the sense of care, security and strengthening of the emotional state.

A rather interesting finding of the present review is the debate surrounding the choice of religion as a means of coping strategy. According to the religious environment and the Saudi cultural context, existential spiritual coping strategies generate hope and meaning [23], a finding that was supported by previous studies [55,56]. The implantation and use of these strategies activate internal motivation for helping and mindfulness and reduce levels of anxiety and depression [57]. Nevertheless, spirituality can be associated with feelings of guilt and may provide additional burden to the caregivers [58], but it does not have a negative impact on their QoL. The benefits are summarized in discovering the meaning of life, reframing difficult situations, providing help to others, having a sense of purpose, accepting the reality, creating a positive thinking for life, assessing satisfaction in a different way and dealing with traumatic experiences. Another study [33] used religion oriented strategies to cope with the demanding role of caring. Religion as a coping strategy offered a positive frame for solving problems, created meaningful purposes and hope, and contributed to the adaptation of the traumatic experience of stroke. Researchers of this study noted that the coping process simulated by existing factors, such as personal skills, social context, physical and psychological components. Moreover, one more study was conducted to investigate the impact of spirituality on carers' QoL [27]. They concluded that there is a positive correlation between spirituality and perceived QoL, while it can moderate the psychological profounds. The recognition and support of spiritual needs is considered timely in the process of support during the period of rehabilitation after stroke for stroke survivors. However, there is paucity in literature data for the study of spirituality as a coping strategy in different and diverse environments of religions and cultures.

A useful distinction of strategies is suggested by the research of El Masry [24], which separates them into cognitive and behavioral techniques. Cognitive strategies include cognitive mechanisms for framing thought and creating perspective, even through adverse events. Thinking changes lead to change in behavior and adaptation of people to new conditions and relationships, by filtering the negative knowledge. Behavioral strategies include the creation of a framework of self-care by the caregivers themselves, by learning to set boundaries and find time and space to unwind through involvement in social activities, while seeking a supportive social system. Similar distinction proposed by the RISE Model of Resilience [30], which included endogenous (individual personality traits) and exogenous variables (social and cultural context) that interact and create a dynamic coping system. The theoretical technique of distinguishing two categories has also been used by other researchers [32], focusing on the interaction of extrinsic (professionals, education, support system) and intrinsic factors (personal beliefs, health well-being, relationships).

Adaptation appears to be suggested by most researchers as the most prevalent and effective coping strategy in improving caregivers' QoL [28,31,35–37], in line with the included studies of Dharma [29] and Yu [13]. The coping strategies identified were acceptance, active coping, positive reframing and planning, substantiating the hypothesis of other researches for their contribution to the reduction of negative feelings of anxiety and sadness [59,60]. Self-efficacy has also be noted to be of substantial importance [35].

Studies of Pucciarelli added two more coping strategies in caring. The first one is caregiver preparedness [25], which helps to better understand the conditions that have a greater impact on survivor-caregiver dyads' QoL. The second moderator is mutuality as a coping mechanism that interferes in caregivers' QoL and highlighted the importance of the binary interpersonal relationship in the recovery trajectory.

Finally, Hallam and Morris [37] introduced "post traumatic growth", as a cognitive coping strategy, consisting of active coping and avoidance coping and encircles the procedure of finding benefit and meaning after trauma.

A summary of all coping strategies identifies in this review is presented in Figure 2.

An important moderating role in the association between caregivers' QoL and coping strategies reiterates the importance of education (Figure 3). Caregivers with higher levels of education are considered to have the potential for greater access to knowledge about stroke, can be more effective to problem-solving tasks and adapt faster to their caring role [13]. Age can also serve as a non-modifiable moderator in QoL, while advancing age was found to be a determinant for adverse outcomes in QoL assessment [61].

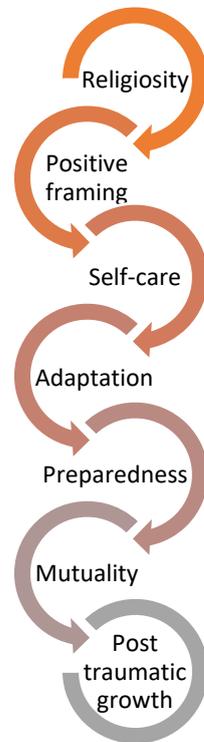


Figure 2. Summary of coping strategies used by included studies.

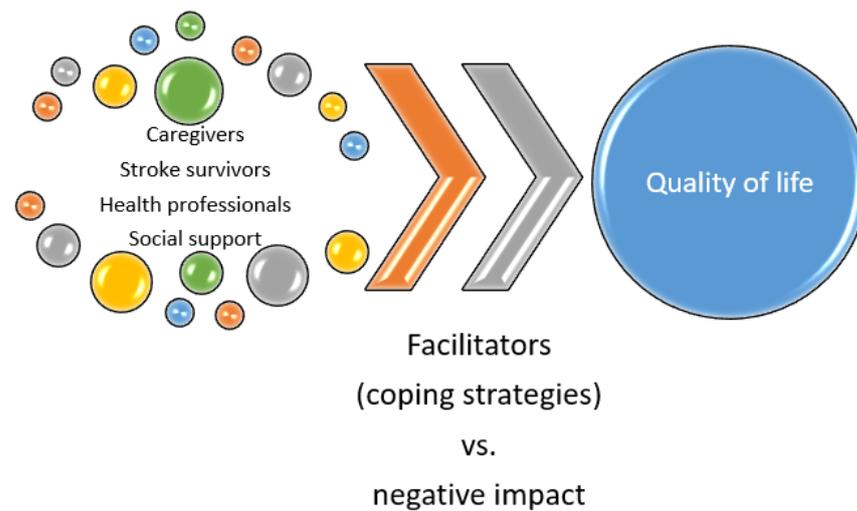


Figure 3. Effect of coping strategies on caregivers' quality of life.

*Limitations and Future Directions*

Some potential limitations should be noted. As many of the included studies consisted of qualitative research, their results had limited generalizability and reduced ability to provide measurable data and be replicable in other contexts. The studies of the present review achieved good quality scores, but they provided insufficient detailed data about stroke severity, patients' disabilities, time since stroke onset, ethnicity, religion, and economic

status. While several studies employed a cross-sectional design, there was a paucity of longitudinal studies, that could provide valuable information regarding the permanence and change of caregiver needs, throughout the spectrum of rehabilitation. Another limitation is that a meta-analysis was not able to be performed because of insufficient quantitative data in the studies. Moreover, the synthesis of the review was limited to peer-reviewed articles in English language. The summary of these articles may have reduced the deep analysis of the data. Although a variety of search engines were used to minimize missed articles, there is a possibility that some studies were missed in this review. Various methodological tools were proposed to measure coping strategies and QoL, although we did not conclude to a specific representative methodological tool. Finally, according to our eligible criteria, no study focusing on secondary caregivers was included.

Future research should be more focused on the process of understanding the diversity of caregivers' needs and the different experiences. It is important to compare the effectiveness of strategies in different cultural, national, and economic contexts. Furthermore, the adoption of specific methodological tools for measuring and evaluating coping strategies and QoL can facilitate the research process around this topic. In addition, the creation of structured intervention programs aimed at coping strategies training would be an important addition to the long and dynamic process of rehabilitation. The design of rehabilitation treatment plans should include training in the psychological factors that can be helpful in self-management.

## 5. Conclusions

This literature review underlines important implications for stroke caregivers but also stroke survivors. In addition to having a significant impact on caregivers' QoL and psychological health, coping strategies also have a significant impact on patients' QoL. Therefore, the study of coping strategies can be used as a psychological reserve in the process of stroke rehabilitation and actively contribute to improving the QoL of both caregivers and stroke survivors. Understanding the psychological effects of stroke and how caregivers' coping strategies and QoL do affect patients' recovery process, can broaden clinical and research interest on stroke prognosis biomarkers and shed new perspectives on practices adopted by health care providers as well as on new policies around the provision of health care services.

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