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REVIEW

# A scoping review on studies about the quality of life of informal caregivers of stroke survivors

**Ana Moura**[1,2,4] · **Filipa Teixeira**[1,4] · **Mariana Amorim**[1,4] · **Ana Henriques**[1,4] · **Conceição Nogueira**[3] · **Elisabete Alves**[1,4]

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## Abstract

**Purpose** To assess the available evidence regarding the quality of life (QoL) of informal caregivers of stroke survivors, by identifying the instruments used to assess QoL, and its associated characteristics.

**Methods** A scoping review was performed, following PRISMA-ScR guidelines. The electronic databases PubMed, ISI Web of Science, PsycINFO, and SciELO were searched for empirical, peer-reviewed, original, and full-length studies on the characteristics influencing the QoL of informal caregivers of stroke survivors. Eligibility and data extraction were conducted by two independent researchers. The main quantitative findings were synthesized, and qualitative data were explored by thematic content analysis.

**Results** The included studies, 56 quantitative, 1 qualitative, and 1 mixed methods, were published between 1999 and 2020. A high heterogeneity was found regarding the assessment of QoL, and the characteristics influencing it. Only one study used an instrument specifically designed to assess the stroke caregivers' QoL. The QoL of informal caregivers was inversely associated with physical and mental health of stroke survivors and caregivers, while stroke characteristics with a better prognosis, caregivers' positive relationships, and a more supportive and participative social context were positively associated to QoL.

**Conclusion** There is a need for standardizing the assessment of the QoL of informal caregivers of stroke survivors, as well as for investing in cross-country/cultural studies with robust mixed methods designs to allow a deeper understanding of the experiences of caregivers. Further research, policies, and practices should consider the diversity and complexity of the characteristics influencing QoL, to empower informal caregivers and improve their QoL.

**Keywords** Informal caregivers · Quality of life · Scoping review · Stroke · Survivors

## Introduction

Worldwide, stroke represents a major health problem, being the second leading cause of death and one of the major causes of disability and incapacity [1–3]. Over the last decades, there has been a decrease in stroke mortality rates along with a rise in stroke incidence at younger ages. This has led to an increased survival among stroke patients [3–5], many of whom with long-lasting consequences that require the assistance and support of a caregiver [6]. Family and friends assume a central role in maintaining the individual's health, particularly in situations of disabling illness, due to its material and affective conditions and characteristics. They represent a fundamental resource in stroke survivors care and post-rehabilitation period, by ensuring practical and emotional support to survivors [6–8]. Therefore, stroke can

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✉ Ana Moura
ana.moura@ispup.up.pt

[1] EPIUnit—Instituto de Saúde Pública, Universidade do Porto, Porto, Portugal

[2] Faculty of Psychology and Education Sciences, Centre for Research and Intervention in Education (CIIE), University of Porto, Porto, Portugal

[3] Faculty of Psychology and Education Sciences, Center for Psychology at University of Porto, University of Porto, Porto, Portugal

[4] Laboratório para a Investigação Integrativa e Translacional em Saúde Populacional (ITR), Porto, Portugal

be a devastating life event not only for those who experience it but also for the people surrounding them [6, 7].

The delivery of informal care is defined as the unpaid assistance directly provided to individuals with limited autonomy, by a non-professional person with whom they have a social relationship (e.g. spouses, parents, children's, other relatives, friends) [9, 10]. Caring for stroke survivors entails a rapid adjustment to the immediate and long-term effects of stroke, requiring varying degrees of caregiving. This often represents a sudden and life-changing demand for informal caregivers of stroke survivors, who frequently feel unprepared to assume this role and responsibilities [8–11]. Such life adjustment may be overwhelming for caregivers, leading to physical and psychological impairments. The combination of these impairments with the socioeconomic repercussions of stroke and the survivors and caregivers' unmet short-, medium-, and long-term needs, can lead to a significant deterioration of caregivers' quality of life (QoL) [11–13]. Additionally, the quality of care provided will impact on stroke survivor's recovery [9, 14], imposing substantial costs for stroke survivors and families, as well as for the healthcare and social systems [9]. Thus, guaranteeing caregivers' well-being and QoL constitute a challenge and should be a priority for health and social policies, practices, and services.

Contrarily to the considerable research on stroke survivors' health and well-being, little attention has been given to informal caregivers' QoL [8]. In fact, literature on informal caregiving has mainly focused on caregivers' burden, depression, anxiety, and psychological distress derived from caring of a stroke survivor [6, 15, 16]. Research on the QoL of stroke survivors' caregivers offers a relevant resource to inform and enrich the development of sustainable and effective-integrated people-centred healthcare guidelines and interventions. However, review studies synthetizing the characteristics influencing the stroke caregivers' QoL are scarce, restricted to specific groups of survivors and caregivers [17, 18], and without specific focus on the QoL of informal caregivers of stroke survivors [19, 20].

Therefore, this scoping review was undertaken in order to assess the available evidence on the QoL of informal caregivers of stroke survivors, namely regarding the instruments used to assess QoL and its associated characteristics. This review will help to identify knowledge gaps, define further research issues [21], and contribute to the development of evidence-based recommendations and strategies to enhance informal caregivers' QoL.

## Methods

### Protocol

This scoping review was conducted and reported following the preferred reporting items for systematic reviews and meta-analysis extension for scoping reviews (PRISMA-ScR) guidelines [22]. A review protocol was developed in advance but was not registered or published prior to conducting the review.

The electronic databases PubMed, Isi Web of Science, PsycINFO, and SciELO were searched for original articles, in January 2021, with no restrictions set for language or time of publication. The search strategy is described in detail in Table 1.

### Selection of sources of evidence

The first and second authors independently screened all the papers retrieved initially, first based on the title and abstract, and second, based on the full texts. Publications with title and

**Table 1** Search strategy

| Research question | What is the body of knowledge on the characteristics influencing the QoL of informal caregivers of stroke survivors? |
|---|---|
| Search expression | ("QoL" OR "quality of life" OR "life quality") AND ("caregivers" OR "informal caregivers" OR "carers" OR "primary caregivers" OR "caregiving" OR "family caregivers" OR "spouse caregiver") AND ("stroke" OR "post stroke" OR "stroke survivor" OR "brain vascular accident" OR "cerebrovascular accident") |
| Electronic databases | The electronic databases PubMed, ISI Web of Science, PsycINFO, and SciELO were searched with no restrictions set for language or time of publications |
| Eligibility criteria | Inclusion criteria: empirical, peer-reviewed, original full-length studies that (1) reported data on the characteristics associated with the QoL of stroke survivors' caregivers; (2) included unpaid adult (≥ 18 years old) informal caregivers; and (3) used quantitative, qualitative, or mixed methodologies |
| | Exclusion criteria: (1) non-original full-length studies (reviews, meta-analyses, study protocols, comments, editorials, newspapers articles, conference proceedings and abstracts, reports, guidelines and grey literature, scales validations, and randomized control trials; (2) studies whose outcomes were not QoL of stroke survivors' informal caregivers or non-related to the research question, namely studies that did not report data on QoL stratified by stroke survivors and informal caregivers, as well as studies assessing caregivers of hospitalized or in-patient/institutionalized stroke survivors and caregivers of multiple chronic health conditions; (3) studies focusing on formal/paid caregivers; (4) articles written in languages other than English, French, Spanish, or Portuguese |

abstracts lacking adequate information to determine inclusion/exclusion criteria underwent full-text review. The process was crosschecked in both phases. Discrepancies were discussed between authors until consensus was reached. The last author resolved conflicts when consensus was not previously achieved. An almost perfect strength of agreement was achieved in both phases [total percentage of agreement = 95.5%; Cohen's kappa = 0.87, 95% confidence interval (95% CI) 0.80–0.95].

## Data extraction

A standardized data extraction sheet was developed and completed, capturing data on study design, type of methodology, authorship, publication year, country, period of data collection, timing of data collection, participants and sample size, instruments used to assess QoL, QoL outcomes, and its associated characteristics. Quantitative data on informal caregivers' QoL scores were collected, whenever available. To describe the variability of instruments used and the consequent variability of QoL values reported, a forest plot was generated to display the studies' mean (95% CI) value of QoL of informal caregivers, according to each instrument. It was excluded from the analysis: (1) studies not reporting data on overall QoL or on the main domains of the instrument used ($n = 16$); (2) those not reporting scores on a 0–100 scale ($n = 7$); or (3) those that did not reported mean values along with the standard deviations or the 95% CI ($n = 6$). For studies using the same sample, the one that had the largest sample size was selected. Among longitudinal studies, the evaluation of QoL presented was the one farther from the stroke.

All variables whose association with informal caregivers' QoL were tested and reported as statistically significant were retrieved and the directions of the associations were registered. When a study provided estimates adjusted for a different number of potential confounders, the one adjusted for the largest number of variables was selected. Otherwise, crude estimates were extracted.

The main qualitative findings regarding the QoL of informal caregivers were retrieved from qualitative and mixed-methods studies. Qualitative data were inductively synthesized into themes and categories by A.M., according to Braun and Clarke's protocol for thematic content analysis [23]. A triangulation strategy was used to guarantee the rigour and quality of research—F.T. and E.A. collaborated in the development of the coding framework.

# Results

## Selection of sources of evidence

From the 1817 records initially retrieved, 1210 were screened based on title and abstract, being excluded 988 records (Fig. 1). Of the 222 full-text papers reviewed, 54 were considered eligible for final analysis. A backward reference searching was carried out examining the reference lists of eligible publications based on full-text assessment and 4 papers were included. Thus, the final scoping review included 58 papers.

## Characteristics of sources of evidence

### Research design

From the included articles, 40 were cross-sectional studies, 16 were longitudinal studies, 1 had a qualitative design, and 1 was a mixed-methods study (Table 2).

The assessment of the QoL of informal caregivers in the quantitative studies ($n = 56$) relied on 12 different standard instruments, while in the qualitative study, the perception of QoL was explored using semi-structured interviews and in the mixed-methods study through in-depth interviews and focus group discussions. Almost 30% of the studies did not provided information regarding the period of data collection, and among the remaining, this period ranged from approximately two months [37, 38, 41, 52, 54] to five years [45]. The timing of data collection was also highly variable across the studies, ranging from within ten days of stroke onset [70] to seven years post-stroke [45].

### Country and year of publication

The studies were mainly conducted in Brazil ($n = 6$), Canada ($n = 5$), Nigeria ($n = 5$), United States of America ($n = 5$), China ($n = 4$), Italy ($n = 4$), and Turkey ($n = 4$) and were published between 1999 and 2020 (Table 2).

### Participants and sample

As presented in Table 2, the samples of the included studies were composed mostly by informal caregivers ($n = 28$), followed by dyads of stroke survivors and their respective caregivers ($n = 21$), and stroke survivors and informal caregivers who were not dyads ($n = 3$). Four studies used control groups, such as healthy control subjects, dyads of controls and spouses, and caregivers of patients with hypertension, while two studies used comparison groups with non-caregivers and non-spouses. Considering the baseline data of the included studies, the sample sizes ranged from 15 [80] to 43,099 [59] participants.

### Assessment of QoL

Overall, most studies did not include a clear and theoretically supported definition of QoL. Thus, different concepts, such as QoL, health-related quality of life (HRQOL), and

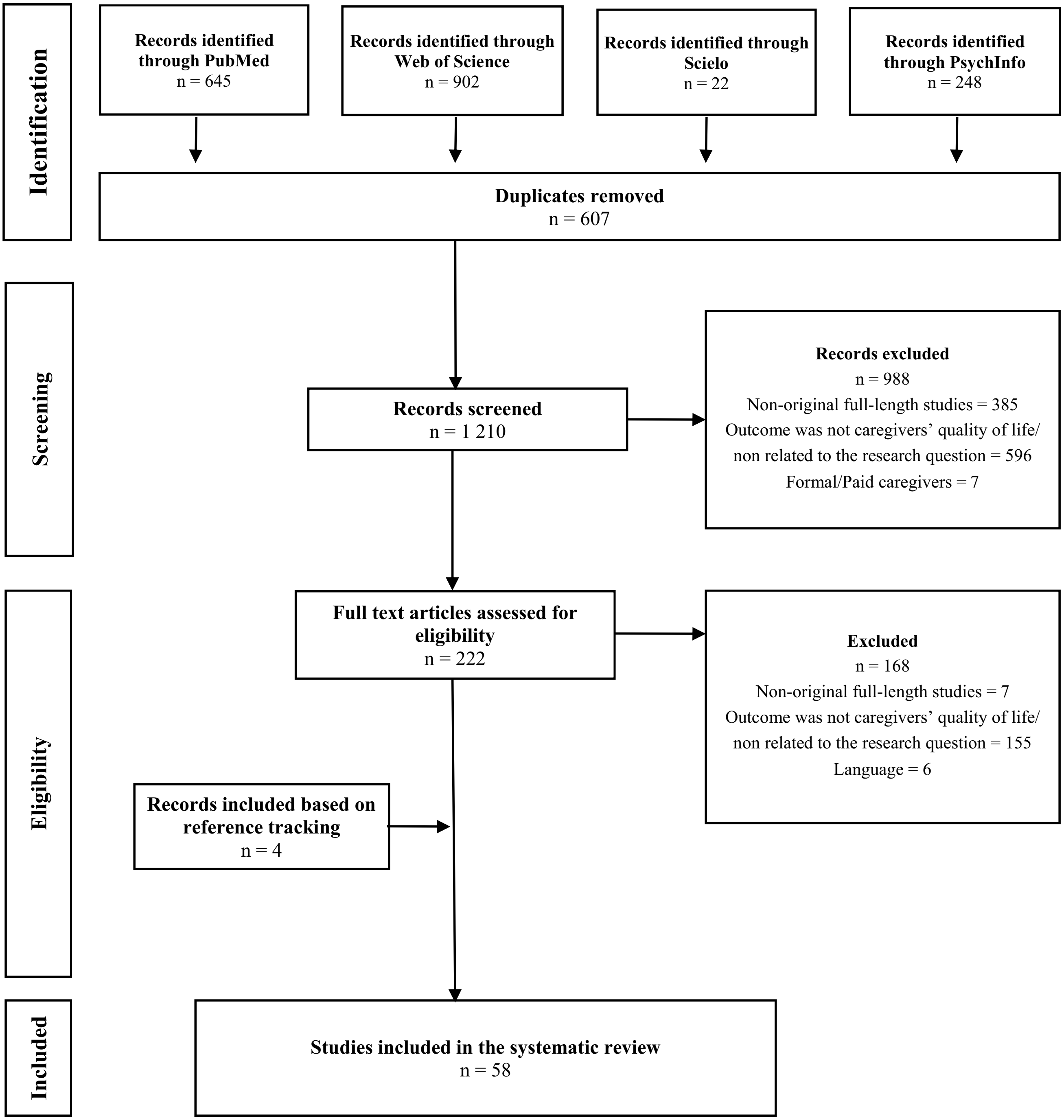
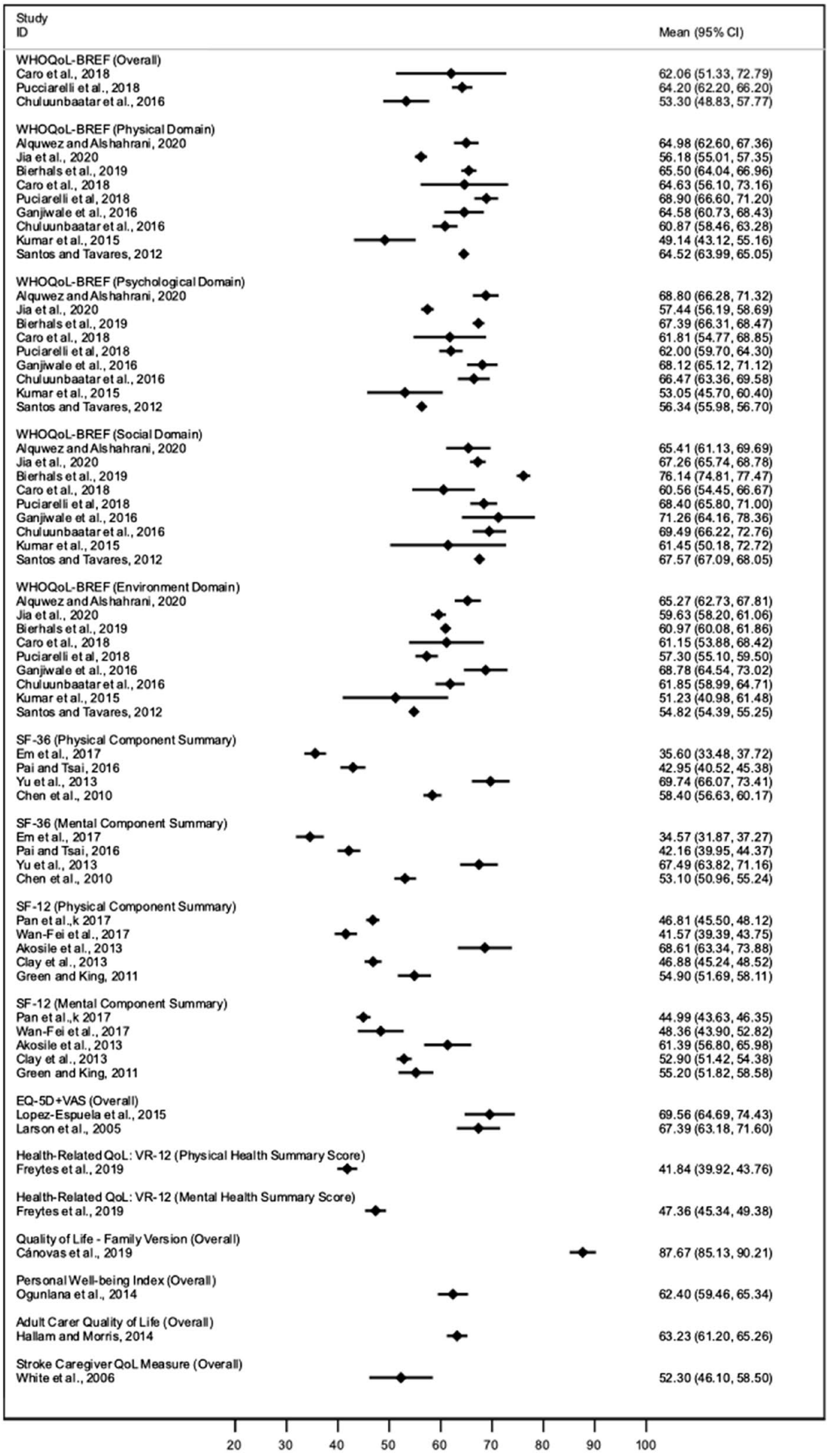


**Fig. 1** Scoping review flowchart

general health emerged as synonyms to sustain the conceptual, theoretical, and methodological features of the studies.

The instrument more frequently used to assess QoL was the WHOQoL-BREF Questionnaire ($n = 18$), followed by the 36-Item Medical Outcomes Short Form (SF-36) ($n = 17$) and the 12-Item Short Form Health Survey (SF-12) ($n = 9$). The remaining twelve studies used nine different instruments to assess the QoL of informal caregivers (Table 2). The diversity of instruments used, each one with different domains and scores, hinders a direct comparison between the studies included in this scoping review.

To describe the variability of QoL values reported across studies, a forest plot was developed comprising data



| Study ID | Mean (95% CI) |
|---|---|
| WHOQoL-BREF (Overall) | |
| Caro et al., 2018 | 62.06 (51.33, 72.79) |
| Pucciarelli et al., 2018 | 64.20 (62.20, 66.20) |
| Chuluunbaatar et al., 2016 | 53.30 (48.83, 57.77) |
| WHOQoL-BREF (Physical Domain) | |
| Alquwez and Alshahrani, 2020 | 64.98 (62.60, 67.36) |
| Jia et al., 2020 | 56.18 (55.01, 57.35) |
| Bierhals et al., 2019 | 65.50 (64.04, 66.96) |
| Caro et al., 2018 | 64.63 (56.10, 73.16) |
| Puciarelli et al, 2018 | 68.90 (66.60, 71.20) |
| Ganjiwale et al., 2016 | 64.58 (60.73, 68.43) |
| Chuluunbaatar et al., 2016 | 60.87 (58.46, 63.28) |
| Kumar et al., 2015 | 49.14 (43.12, 55.16) |
| Santos and Tavares, 2012 | 64.52 (63.99, 65.05) |
| WHOQoL-BREF (Psychological Domain) | |
| Alquwez and Alshahrani, 2020 | 68.80 (66.28, 71.32) |
| Jia et al., 2020 | 57.44 (56.19, 58.69) |
| Bierhals et al., 2019 | 67.39 (66.31, 68.47) |
| Caro et al., 2018 | 61.81 (54.77, 68.85) |
| Puciarelli et al, 2018 | 62.00 (59.70, 64.30) |
| Ganjiwale et al., 2016 | 68.12 (65.12, 71.12) |
| Chuluunbaatar et al., 2016 | 66.47 (63.36, 69.58) |
| Kumar et al., 2015 | 53.05 (45.70, 60.40) |
| Santos and Tavares, 2012 | 56.34 (55.98, 56.70) |
| WHOQoL-BREF (Social Domain) | |
| Alquwez and Alshahrani, 2020 | 65.41 (61.13, 69.69) |
| Jia et al., 2020 | 67.26 (65.74, 68.78) |
| Bierhals et al., 2019 | 76.14 (74.81, 77.47) |
| Caro et al., 2018 | 60.56 (54.45, 66.67) |
| Puciarelli et al, 2018 | 68.40 (65.80, 71.00) |
| Ganjiwale et al., 2016 | 71.26 (64.16, 78.36) |
| Chuluunbaatar et al., 2016 | 69.49 (66.22, 72.76) |
| Kumar et al., 2015 | 61.45 (50.18, 72.72) |
| Santos and Tavares, 2012 | 67.57 (67.09, 68.05) |
| WHOQoL-BREF (Environment Domain) | |
| Alquwez and Alshahrani, 2020 | 65.27 (62.73, 67.81) |
| Jia et al., 2020 | 59.63 (58.20, 61.06) |
| Bierhals et al., 2019 | 60.97 (60.08, 61.86) |
| Caro et al., 2018 | 61.15 (53.88, 68.42) |
| Puciarelli et al, 2018 | 57.30 (55.10, 59.50) |
| Ganjiwale et al., 2016 | 68.78 (64.54, 73.02) |
| Chuluunbaatar et al., 2016 | 61.85 (58.99, 64.71) |
| Kumar et al., 2015 | 51.23 (40.98, 61.48) |
| Santos and Tavares, 2012 | 54.82 (54.39, 55.25) |
| SF-36 (Physical Component Summary) | |
| Em et al., 2017 | 35.60 (33.48, 37.72) |
| Pai and Tsai, 2016 | 42.95 (40.52, 45.38) |
| Yu et al., 2013 | 69.74 (66.07, 73.41) |
| Chen et al., 2010 | 58.40 (56.63, 60.17) |
| SF-36 (Mental Component Summary) | |
| Em et al., 2017 | 34.57 (31.87, 37.27) |
| Pai and Tsai, 2016 | 42.16 (39.95, 44.37) |
| Yu et al., 2013 | 67.49 (63.82, 71.16) |
| Chen et al., 2010 | 53.10 (50.96, 55.24) |
| SF-12 (Physical Component Summary) | |
| Pan et al.,k 2017 | 46.81 (45.50, 48.12) |
| Wan-Fei et al., 2017 | 41.57 (39.39, 43.75) |
| Akosile et al., 2013 | 68.61 (63.34, 73.88) |
| Clay et al., 2013 | 46.88 (45.24, 48.52) |
| Green and King, 2011 | 54.90 (51.69, 58.11) |
| SF-12 (Mental Component Summary) | |
| Pan et al.,k 2017 | 44.99 (43.63, 46.35) |
| Wan-Fei et al., 2017 | 48.36 (43.90, 52.82) |
| Akosile et al., 2013 | 61.39 (56.80, 65.98) |
| Clay et al., 2013 | 52.90 (51.42, 54.38) |
| Green and King, 2011 | 55.20 (51.82, 58.58) |
| EQ-5D+VAS (Overall) | |
| Lopez-Espuela et al., 2015 | 69.56 (64.69, 74.43) |
| Larson et al., 2005 | 67.39 (63.18, 71.60) |
| Health-Related QoL: VR-12 (Physical Health Summary Score) | |
| Freytes et al., 2019 | 41.84 (39.92, 43.76) |
| Health-Related QoL: VR-12 (Mental Health Summary Score) | |
| Freytes et al., 2019 | 47.36 (45.34, 49.38) |
| Quality of Life - Family Version (Overall) | |
| Cánovas et al., 2019 | 87.67 (85.13, 90.21) |
| Personal Well-being Index (Overall) | |
| Ogunlana et al., 2014 | 62.40 (59.46, 65.34) |
| Adult Carer Quality of Life (Overall) | |
| Hallam and Morris, 2014 | 63.23 (61.20, 65.26) |
| Stroke Caregiver QoL Measure (Overall) | |
| White et al., 2006 | 52.30 (46.10, 58.50) |

**Fig. 2** Mean (95 % Confidence Interval) quality of life (QoL) of caregivers of stroke survivors, according with the instrument used. Notes: 95% CI, 95% Confidence interval. Studies not reporting: (1) data on overall QoL or on main domains of the instrument; (2) mean values along with the standard deviations or the 95% CI; or (2) scores in a 0–100 scale, were excluded. If more than one study using the same sample were available, the one that had the largest sample size was selected. Among longitudinal studies, the evaluation of QoL presented was the one farther from the stroke

**Table 2** Main characteristics of the included studies ($n = 58$)

| Publication | Country | Period of data collection | Timing of data collection | Participants and sample | Assessment of QoL |
|---|---|---|---|---|---|
| **Cross sectional studies** | | | | | |
| Alquwez and Alshahrani [24] | Saudi Arabia | June to November 2019 | – | 123 informal caregivers | WHOQoL-BREF |
| Freytes et al. [25] | USA | 2013–2014 | – | 109 informal caregivers | Health-Related Quality of Life: Veterans Rand 12-Item Health Survey |
| Jia et al. [26] | China | June to October 2019 | – | 305 informal caregivers | WHOQoL-BREF |
| Özdemir and Parker [27] | Turkey | January to June 2017 | At least 3 months after stroke | 97 dyads (stroke survivors and their informal caregivers) | SF-36 |
| Cánovas et al. [28] | Cuba | 2018 | – | 207 dyads (stroke survivors and their informal caregivers) | Quality of Life – Family Version |
| Celik and Kara [29] | Turkey | October 2013 to February 2014 | – | 100 dyads (stroke survivors and their informal caregivers) | SF-36 |
| Masoudian et al. [30] | Iran | May 2016 to May 2017 | At least 6 weeks after stroke | 62 informal caregivers | SF-36 |
| Caro et al. [31] | Brazil | January to May 2014 | At least 6 months after stroke | 30 informal caregivers | WHOQoL-BREF |
| Tsai et al. [32] | Taiwan | – | Within 1 year after discharge | 126 informal caregivers | Caregiver Quality of Life Index |
| Caro et al. [33] | Brazil | November 2013 to May 2014 | Within 6 to 72 months after stroke | 30 dyads (stroke survivors and their informal caregivers) | WHOQoL-BREF |
| Efi et al. [34] | Greece | January to June 2015 | At least 6 weeks after stroke | 150 informal caregivers | SF-12 |
| Em et al. [35] | Turkey | March 2012 to November 2013 | Within 4 weeks to 24 months after stroke | 76 stroke survivors + 76 caregivers vs 94 healthy control subjects | SF-36 |
| Pan et al. [36] | China | October 2013 to February 2014 | – | 126 adult child caregivers of parent stroke survivors | SF-12 |
| Wan-Fei et al. [37] | Malaysia | December 2014 to February 2015 | – | 30 dyads (stroke survivors and their informal caregivers) | SF-12 |
| Costa et al. [38] | Brazil | April to June 2013 | – | 136 informal caregivers | SF-36 |
| Ganjiwale et al. [39] | India | July 2012 to June 2013 | At least 6 months after stroke | 54 dyads (stroke survivors and their informal caregivers) | WHOQoL-BREF |
| Pai and Tsai [40] | Taiwan | March to November 2012 | – | 77 informal caregivers | SF-36 |
| Costa et al. [41] | Brazil | April to June 2013 | – | 136 informal caregivers | SF-36 |
| Jeong et al., 2015 [42] | Republic of Korea | October 2013 to April 2014 | – | 238 dyads (stroke survivors and their informal caregivers) | WHOQoL-BREF |
| Kumar et al. [43] | India | January to May 2014 | At least 1 month after discharge | 22 caregivers | WHOQoL-BREF |
| López-Espuela et al. [44] | Spain | June to December 2013 | Follow-up appointments after stroke (no references to time of stroke onset) | 48 informal caregivers | EQ-5D |
| Persson et al. [45] | Sweden | 1998—2003 | 7 years after stroke | 248 dyads (stroke survivors and their spouse's caregivers) vs 245 dyads controls and spouses | SF-36 |
| Hallam and Morris [46] | UK | – | At least 18 months after stroke | 71 informal caregivers | Adult Carer Quality of Life |

**Table 2** (continued)

| Publication | Country | Period of data collection | Timing of data collection | Participants and sample | Assessment of QoL |
|---|---|---|---|---|---|
| Ogunlana et al., 2014 [47] | Nigeria | – | At least 6 months after stroke | 130 informal caregivers | Personal Well-being index |
| Akosile et al. [48] | Nigeria | – | – | 91 caregivers | SF-12 |
| Clay et al. [49] | USA | January 2003 to October 2007 | – | 146 dyads (stroke survivors and their informal caregivers) | SF-12 |
| Hilton et al. [50] | South Africa | January to June 2011 | Within the 6 to 36 months post-stroke window | 35 dyads (stroke survivors and their informal caregivers) | EQ-5D |
| Vincent-Onabajo et al. [51] | Nigeria | – | At physiotherapy sessions after stroke (no references to time of stroke onset) | 59 informal caregivers | WHOQoL-BREF |
| Yu et al. [52] | China | July to September 2009 | – | 121 dyads (stroke survivors and their informal caregivers) | SF-36 |
| Kniepmann, [53] | USA | – | Within 6 to 24 months after stroke | 20 informal female caregivers | SF-36 |
| Santos and Tavares [54] | Brazil | April to June 2010 | Stroke between July 2003 and December 2008 | 46 caregivers | WHOQoL-BREF |
| Akosile et al. [55] | Nigeria | – | – | 91 dyads (stroke survivors and their informal caregivers) | SF-12 |
| McPherson et al. [56] | Canada | Between 2007 and 2008 |  | 56 dyads (stroke survivors and their partners | SF-36 |
| Chen et al. [57] | China | April 2006 to February 2007 | – | 123 dyads (stroke survivors and their informal caregivers) | SF-36 |
| Marco et al. [58] | Spain | January 1998 to May 2000 | 2 years after stroke | 215 informal caregivers | SF-36 |
| Roth et al. [59] | USA | January 2003 to October 2007 | - | 5159 caregivers vs 37,940 non-caregivers | SF-12 |
| Gunduz and Erhan [60] | Turkey | – | Within 6 months to 5 years after stroke | 47 spouses' caregivers and 26 healthy controls | SF-36 |
| Fatoye et al. [61] | Nigeria | May 2004 to August 2005 | – | 103 stroke caregivers and 103 controls (relatives' caregivers of survivors on treatment for hypertension) | WHOQoL-BREF |
| Morimoto et al. [62] | Japan | – | – | 100 dyads (stroke survivors and their informal caregivers) | SF-12 |
| Carod-Artal et al. [63] | Spain | July to December 1996 | 12 months after stroke | 80 informal caregivers | SmithKline Beecham Quality of Life Scale |
| **Longitudinal studies** |  |  |  |  |  |
| Labberton et al. [64] | Norway | February 2012 to March 2013 | 3 (T1) and 12 months (T2) after discharge | T1: 320 informal caregivers and 368 stroke survivors / T2: 326 informal caregivers and 383 stroke survivors | EQ-5D-3L |

**Table 2** (continued)

| Publication | Country | Period of data collection | Timing of data collection | Participants and sample | Assessment of QoL |
|---|---|---|---|---|---|
| Pucciarelli et al. [65] | Italy | – | At discharge (T1) and 12 months after stroke survivors' discharge (T2) | 222 dyads (stroke survivors and their informal caregivers) | WHOQoL-BREF |
| Pucciarelli et al. [66] | Italy | – | At discharge (T1), 3 (T2),6 (T3), 9 (T4), and 12 months (T5) after stroke survivors' discharge | 213 dyads (stroke survivors and their informal caregivers) | WHOQoL-BREF |
| Bierhals [67] | Brazil | May 2016 to June 2017 | 1 week (T1) and 2 months (T2) after discharge | 48 family caregivers (20 spouses vs 28 non-spouses: adult children) | WHOQoL-BREF |
| Pucciarelli et al. [68] | Italy | June 2013 to May 2016 | At discharge (T1), 3 (T2),6 (T3), 9 (T4), and 12 months (T5) after stroke survivors' discharge | T1: 244 dyads (stroke survivors and their informal carers)/ T2: 187 dyads / T3: 158 dyads / T4: 146 dyads / T5: 133 dyads | WHOQoL-BREF |
| Pucciarelli et al. [69] | Italy | June 2013 to May 2016 | At discharge (T1), 3 (T2), 6 (T3), 9 (T4), and 12 months (T5) after stroke survivors' discharge | 226 dyads (stroke survivors and their informal caregivers) | WHOQoL-BREF |
| Chuluunbaatar et al. [70] | Mongolia | – | Within 10 days of stroke onset (T1) and 1-year post-stroke (T2) | T1: 288 stroke survivors and 233 informal caregivers / T2: 155 stroke survivors and 88 informal caregivers | WHOQoL-BREF |
| Godwin et al. [71] | USA | 2001–2005 | 2 years after stroke | 30 dyads (stroke survivors and their informal caregivers) | SF-36 |
| Green and King [72] | Canada | – | At discharge (T1), 1 (T2), 2 (T3), and 3 (T4) months after stroke | T1: 38 male survivors and their wife-caregivers/ T2: 37 male survivors and their wife-caregivers / T3 and T4: 35 male survivors and their wife-caregivers | SF-12 |
| Wilz and Soellner [73] | Germany | 2001–2004 | 4.3 months (T1) and 1 year (T2) after stroke | 70 dyads (stroke survivors and their informal caregivers) | WHOQoL-BREF |
| Nir et al. [74] | Israel | – | 2 weeks after stroke (T1), 3 (T2), and 6 months (T3) after stroke | T1: 140 informal caregivers / T2: 137 informal caregivers / T3: 132 informal caregivers | WHOQoL-BREF |
| Schlote et al. [75] | Germany | May 2002 to March 2004 | Admission to in-patient rehabilitation (T1), 6 (T2), and 12 months (T3) after discharge | 64 informal caregivers | SF-36 |
| White et al. [76] | Canada | – | 18 (T1) and 24 months (T2) after stroke | 52 informal caregivers | Stroke Caregiver QoL Measure |
| Jonsson et al. [77] | Sweden | March 2001 to February 2002 | 4 (T1) and 16 months (T2) after stroke (during follow-up visits) | 304 stroke survivors and 234 caregivers | SF-36 |

**Table 2** (continued)

| Publication | Country | Period of data collection | Timing of data collection | Participants and sample | Assessment of QoL |
|---|---|---|---|---|---|
| Larson et al. [78] | Sweden | November 2000 to July 2002 | Admission to a stroke unit (T1), 6 (T2), and 12 months (T3) after stroke | 100 spouses' caregivers | EQ-VAS |
| White et al. [79] | Canada | – | 1 (T1) and 2 years (T2) after stroke | 97 dyads (stroke survivors and their informal caregivers) | Numeric Rating Scale |
| **Qualitative studies** | | | | | |
| Low et al. [80] | Canada | – | – | 15 informal caregivers | Semi-structured interview |
| **Mixed-methods studies** | | | | | |
| Khalid et al.* [81] | Pakistan | June 2014 | At least 1-month post-stroke | (1) 350 dyads (stroke survivors and their informal caregivers)<br>(2) 20 informal caregivers | (1) RAND-36<br>(2) In-depth interviews and focus group |

*Extracted data regarding the QoL of informal caregivers of stroke survivors derive only from the qualitative data

regarding the studies' mean (95%CI) QoL, according to the instrument used (Fig. 2). Among studies using the WHO-QoL-BREF Questionnaire mean (95% CI) scores ranged between 49.14 (43.12–55.16) for the physical domain and 76.14 (74.81–77.47) for the social domain (Fig. 2). A slightly higher variability, although with lower estimates of caregivers' QoL, was observed among studies using the SF-36, with mean (95% CI) scores ranging from 34.57 (31.87–37.27) on mental component summary (MCS) to 69.74 (66.0–73.41) on physical component summary (PCS); while the mean (95% CI) of QoL ranged between 41.57 (39.39–43.75) and 68.61 (63.34–73.88) both on PCS, among studies resorting to SF-12 scale. The mixed-methods study only assessed the QoL of informal caregivers qualitatively, through the analysis of their perceptions regarding life changes after stroke, while the qualitative study explored the impact of the two different methods of service delivery (domiciliary and day hospital) on caregivers' QoL.

## Synthesis of results

The majority of studies reported issues related to physical and mental health of stroke survivors and caregivers as negatively influencing caregiver's perception of their own QoL (Table 3). Caregivers' and stroke survivors' higher levels of burden, depression, and anxiety were consistently reported as characteristics predicting poorer QoL among informal caregivers. Furthermore, caregivers with health problems, and with poor or fair perceived health status also presented lower levels of perceived physical QoL. Inversely, caring for stroke survivors with fewer health problems and higher levels of QoL was associated with a better perception QoL. Also, caregivers with chronic diseases who presented higher vitality, better physical and mental health and who use more frequently coping and planning strategies, as well as those reporting a post-traumatic growth and higher levels of resilience and well-being had significantly higher levels of QoL.

Data on sociodemographic characteristics, namely sex and age, revealed inconsistent results across studies. Although the majority of studies supported that being an older and female caregiver were associated with a poorer perception of QoL, some studies presented opposite evidence, stating that female sex and increased age were positively associated with better QoL. Similarly, while some authors advocated that caring for older and female stroke survivors were associated with poorer levels of physical and social QoL, others described positive associations between female sex and older age of survivors and overall, physical and mental QoL of informal caregivers. The QoL of caregivers, especially on overall, physical and mental QoL domains, was perceived as better when both caregivers and survivors had a higher education and were employed. Overall, caregivers who reported lower monthly income, medical fees

**Table 3** Characteristics associated with the informal caregivers' perceptions of quality of life (QoL)

| Characteristics | Caregivers' QoL | |
|---|---|---|
| | Better perception | Poorer perception |
| **Physical and mental health** | | |
| Burden | | ■ Caregivers with higher levels of burden: [41][d,e], [25][h], [28, 30][a], [31][d,f], [32][a], [33][a], [34][h], [40][d,h], [42][a], [43][d,h,j], [44][a], [48][d,g,h], [53][h], [62][d,e,g,h], [69][d,h], [72][a], [74][a]<br>■ Stroke survivors with high levels of burden: [47][a] |
| Depression | | ■ Caregivers with higher levels of depression: [37][d,h], [25][h], [34][d,h], [35][d,e,g,h,j], [57][d,h], [58][a,‡], [63, 64, 69][d,h], [71][8], [72][d,h]<br>■ Stroke survivors with higher levels of depression: [45][d,h,j], [57][d,h], [58][d,e,h,j], [61][d,h,j], [64, 69][d,h], [72][h], [75][d,e,g,h,j], [77][d,e] |
| Physical comorbidities | ■ Stroke survivors with fewer health problems: [58][h]<br>■ Caregivers with chronic diseases: [26][f,h] | ■ Caregivers with health problems: [52][d], [54][4,6,8,10], [34][d,h], [36][d], [57][d], [58][d], [62][d,g], [71][d], [74][a] |
| Perceived health status | ■ Caregivers with better self-rated health: [32][a], [42][a]<br>■ Caregivers with higher vitality, physical and mental health: [79][a] | ■ Caregivers with poor or fair self-rated health: [32][a]<br>■ Caregivers with poor physical health: [70][a] |
| Anxiety | | ■ Caregivers with higher levels of anxiety: [37][d,h],[81][d,e], [34][d,h], [35][d,g,h,j], [64] |
| Stroke survivor QoL | ■ Higher QoL: [27][e], [56, 64, 72][h] | |
| Caregivers coping strategies | ■ Using coping and planning strategies: [52][h], [24][d,f], [46] | |
| Post-traumatic growth | ■ Caregivers post-traumatic growth: [46] | |
| Resilience | ■ Caregivers higher levels of resilience: [26][f,j] | |
| Well-being | ■ Caregivers higher levels of well-being: [78][a] | |
| **Sociodemographic** | | |
| Age | ■ Younger caregivers: [82][d,f,j], [79][a]<br>■ Older caregivers: [83][a], [26][f]<br>Younger stroke survivors: [38][j]<br>■ Older stroke survivors: [47][a], [61][d], [68][a] | ■ Older caregivers: [41][d], [45][a], [24][j], [27][d,e,j], [29][d,g], [36][d], [40][d], [46, 47][a], [50][a], [55][a], [56][d], [57][d], [58][d], [61][d,h,j], [62][d], [68][a], [71][d]<br>■ Older stroke survivors: [36][d], [56][d], [57][d], [77][d,j]<br>■ Younger caregivers: [41][d] |
| Sex | ■ Female caregivers: [24][d], [47][a], [61][d,f,h,j]<br>■ Female stroke survivors: [77][d,h] | ■ Female caregivers: [41][d], [70][h], [24][f,j], [29][d,g,j],[90][d], [48][d,g,h], [55][h],[105][h], [60][d,e,j], [74][1], [75][d,e]<br>■ Female stroke survivors: [36][d], [61][d] |
| Educational level | ■ Caregivers with higher educational levels: [52][d,h], [45][d], [29][d,e,g,h,j], [42][a], [51][d], [61][d], [68][a], [69][d,h]<br>■ Stroke survivors with higher educational level: [38][h] | ■ Caregivers with lower educational levels: [32][a], [57][d], [60][d,h] |
| Financial resources | ■ Caregivers with higher income: [41][d,h], [42][a], [78][a],[80][f,h]<br>■ Caregivers with lower income: [29][h] | ■ Caregivers with lower monthly income: [32][a], [36][h]<br>■ Caregivers with medical fees paid by spouses: [32][a]<br>■ Caregivers with financial difficulties: [70][d] |
| Employment status | ■ Working caregivers: [24][d], [29][d,e,g], [36][d], [42][a], [51][d,f]<br>■ Working survivors: [42][a], [73][d,f,h] | |
| Ethnicity | ■ African-American caregivers: [49][h] | |

**Table 3** (continued)

| Characteristics | Caregivers' QoL | |
|---|---|---|
| | Better perception | Poorer perception |
| **Stroke characteristics** | | |
| Functional status | ■ Stroke survivor's functional independence: [38][h], [52][h], [45][d,e,g,h], [80, 27][d], [29][g],[89][d,h], [39][d,i], [47][1], [58][1], [63, 69][d,h], [72][1], [77][d,h,j], [81]<br>■ Moderate stroke survivor's physical impairment: [79][a]<br>■ Stroke survivor's ability to communicate: [34][h]<br>■ Stroke survivors with better cognitive function: [32][a] | ■ Stroke survivor's physical disabilities: [45][d,h], [80, 27][d,e], [36][d], [47][a], [63],<br>Stroke survivors with cognitive impairment: [45][d], [61][f], [77][g] |
| Stroke consequences | ■ Stroke survivors without assistance devices, nasogastric or tracheostomy tubes: [32][a] | ■ Stroke survivors with aphasia/dysphasia: [80, 79][a]<br>■ Stroke survivor with paresis: [61][j]<br>■ Cognitive/emotional deficits: [25][h] |
| Time from stroke | ■ Shorter post-stroke duration: [47][a], [51][f] | |
| Duration of hospitalization | | ■ Higher duration of hospitalization: [42][a] |
| Stroke classification | ■ Hemorrhagic stroke: [34][d] | ■ Intracerebral hemorrhagic stroke: [64]<br>■ Ischemic stroke: [64] |
| **Household composition and relationship** | | |
| Kin relationship | ■ Family caregivers: [61][d,f,h,j]<br>■ Sons/daughters: [58][d]<br>■ Parents and siblings: [34][d]<br>■ Non-spousal caregivers: [83][i] | ■ Family caregivers: [52][d],[103][a]<br>■ Spouses caregivers: [42][a]<br>■ Parents: [26][d]<br>■ Siblings: [24][j]<br>■ Sons/daughters: [24][j] |
| Marital status | ■ Single caregivers: [34][d], [47][a]<br>■ Married caregivers: [41][e,h]<br>■ Married stroke survivors: [38][e] | |
| Relationship status | ■ [36]Caregivers with higher levels of mutuality†: [d,h], [65][d,h,j]<br>■ Caregivers with higher marital satisfaction: [72][d,h]<br>■ Caregivers with higher relationship satisfaction: [56][h] | ■ Caregivers who perceived stroke survivors as cooperatives: [61][d] |
| Household composition | ■ Caregivers living with the survivor: [68][a] | ■ Caregivers living with a smaller number of family members: [57][a]<br>■ Caregivers living with the survivor: [74][a] |
| Having children | | ■ Caregivers with children: [34][d] |
| **Care trajectory** | | |
| Information and training | ■ Preparedness, training and feelings of mastery: [83][i], [29][g,h], [69][d], [81]<br>■ Previous experience of care: [29][g]<br>■ Tele-health service: [81] | ■ Previous experience of care: [29][d] |
| Length and daily hours of care | ■ Longer duration of care: [61][d,h,j] | ■ Longer duration of care: [27][a,d,j,k], [29][d,g], [42][a]<br>■ Higher amount of time spent on caregiving: [52][h], [34][d,h], [42][a]<br>■ Shorter duration of care: [36][h] |

**Table 3** (continued)

| Characteristics | Caregivers' QoL | |
|---|---|---|
| | Better perception | Poorer perception |
| Assistance | ■ Do not hire non-family caregivers: [32][a]<br>■ Instrumental support inside and outside the home: [74][a]<br>■ General Practice system to manage the physical and mental health and accessibility conditions of stroke survivors: [81]<br>■ Holistic care to stroke survivors and caregivers provided by the health management teams: [81] | |
| Awareness of stroke | | ■ Caregivers with higher levels of awareness of stroke impact: [40][d]lePara> |
| Caregiver role | | ■ Caregivers with a negative perception of their role: [56][a] |
| Self-efficacy | ■ Caregivers self-efficacy: [26][d,f,h,j] | |
| **Social context** | | |
| Social support | ■ Caregivers with better social networks: [57][d,h]<br>■ Caregivers confidence in the support system: [74][a]<br>■ Emotional support: [81]<br>■ Support from family, friends and significant others: [24][d,f,h,j]<br>■ Encouragement and guidance: [81]<br>■ Give affection/encouragement and hope to survivors: [81] | ■ Caregivers perceived lack of social support: [45][h]<br>■ Caregivers receiving more support: [49][d]<br>■ Caregivers who need help and advice: [74][a]<br>■ Isolation and loneliness: [81]<br>■ Geographic distance from other sources of support: [80] |
| Social participation | ■ Stroke survivor's social participation: [83][a], [77][d]<br>■ Joint participation in social activities: [80] | |
| Life situation | | ■ Caregivers poor life situation: [78][a] |
| Spirituality | ■ Stroke survivors and caregiver's spirituality: [66][d,h] | |

All presented associations are significant at $p \leq 0.05$

As with the other dimensions (physical and mental health, sociodemographic characteristics, stroke characteristics, household composition and relationship and care trajectory), the social context dimension should be in bold

[†] Mutuality: positive quality of the relationship between

[‡] Highest in mental health and vitality domains a caregiver and a care receiver

[a] Overall QoL

[b] All SF-36 domains, except bodily pain

[c] All SF-36 domains, except mental health

[d] Physical health domains (bodily pain; functional capacity, mobility, pain, physical component summary, physical functioning, physical health, physical problems, physical role, role limitations because of physical problems, sphincters, vitality)

[e] Emotional health domains (emotional aspects, emotional role, role limitations because of emotional problems)

[f] Environmental health domain

[g] General health domain

[h] Mental health domains (mental health, mental component summary, psychological health)

[i] Resources domain (personal and environmental resources)

[j] Social health domains (social functioning, social relationships)

[k] Change in health

paid by spouses and financial difficulties were more likely to describe a lower perception of QoL. However, one study reported that caregivers with lower income had better QoL in comparison with those with higher income. Only one study assessed ethnicity, concluding that African-American caregivers perceived their QoL as better in comparison with Caucasian's caregivers.

The association between stroke characteristics and informal caregivers' QoL was assessed in less than half of the studies included in this scoping review. Caring for independent stroke survivors, with moderate physical impairments, ability to communicate, and better cognitive function was associated with higher QoL among informal caregivers. Similarly, a shorter post-stroke duration, having a hemorrhagic stroke and not using assistance devices, nasogastric or tracheostomy tubes were described as characteristics positively associated with QoL. On the other hand, caring for survivors with physical disabilities, cognitive impairments, aphasia/dysphasia, paresis, and cognitive/emotional deficits, who were hospitalized for a longer period of time and who had an intracerebral hemorrhagic or ischemic stroke negatively influence caregivers' QoL.

Studies assessing the nature of the relationship with the survivor, the informal caregivers' marital status, and household composition revealed scattered and conflicting results, hampering the identification of positive or negative associations with the QoL. The relationship status, namely, mutuality, marital satisfaction, and relationship satisfaction were mentioned as characteristics that positively influenced caregivers' mental and physical QoL. Contrariwise, caregivers who perceived stroke survivors as cooperatives and with children tended to report lower levels of physical QoL.

Spending more daily hours caring for survivors, presenting higher levels of awareness of stroke impact and having a negative perception of the caregiver role were associated with poorer perceptions of QoL. Being better prepared, having training and feelings of mastery, taking advantage of tele-health services, not hiring non-family caregivers, having more instrumental support inside and outside the home, having a general practice system and a holist care directed to informal caregivers and survivors and having a greater self-efficacy positively influenced the caregivers' QoL. Nevertheless, inconsistent results were found concerning the duration of care, with studies simultaneously supporting an association with better and poorer QoL. Also, the previous experience of care was simultaneously reported as a predictor of higher general health and lower physical health among informal caregivers.

Characteristics related with social context were less frequently assessed. Lower levels of QoL were associated with lack of social support, need of help and advice, isolation and loneliness, higher geographic distance from sources of support and the caregivers' perception of poor life situation. Contrariwise, caregivers who reported more confidence in the support system, higher levels of emotional support, those who received support from family, friends, and significant others, and encouragement and guidance in the caregiver's role, as well as those who ensure affection and hope to survivors, presented better QoL. However, one study concluded that informal caregivers' physical QoL was inversely associated with receiving more support. Higher stroke survivors' social participation as well as the joint participation of both informal caregivers and survivors in social activities, and the stroke survivors and caregiver's spirituality, were also described as being positively associated with the overall, physical and mental QoL of informal caregivers.

## Discussion

### Summary of evidence

This scoping review highlights the variety of dimensions and instruments used to assess the QoL of informal caregivers of stroke survivors, as well as the exploration of a wide range of associated characteristics.

The heterogeneous assessment of QoL, namely regarding the variability of instruments used, highly influenced the studies' results. The smaller dispersion found in the results evaluated with specific QoL instruments (e.g. WHOQoL-BREF) suggests that the studies that use these instruments are evaluating the QoL phenomena in a more homogeneous way, allowing more reliable comparisons and interpretations. Therefore, the variability of instruments used compromises the comparability of findings, and consequently, the development of systematic reviews and meta-analyses on the QoL of informal caregivers and may partly justify the report of contradictory results across studies. Moreover, only one study used an instrument specifically designed to assess the impact of caregiving on the stroke caregivers' QoL [83] while the majority resourced to generic instruments to access well-being, HRQOL, and general health as proxies of QoL. Thus, literature in this field may be neglecting specific dimensions of QoL that are particularly relevant for informal caregivers and which may not be addressed in instruments for the general population or in those assessing other constructs than QoL. In this context, the wide use of reliable and valid instruments specifically designed to assess the QoL of informal caregivers of stroke survivors may contribute to broaden the understanding of their QoL, assisting researchers and practitioners to unravel the mechanisms behind some contradictory findings.

The results of this study revealed that the QoL of informal caregivers of stroke survivors was negatively influenced by the physical and mental health status of both caregivers and survivors, while stroke characteristics with a better prognosis, caregivers' positive relationships status and a more supportive and participative social context were positively associated with QoL. The inconclusive results regarding age, sex, stroke classification, household composition, and care trajectory calls for the development of robust mixed-methods studies, performed in different contexts and cultures, specifically designed to explore and understand the characteristics influencing the QoL of this specific population.

The QoL of informal caregivers was inversely associated with greater burden, depressive symptoms, and anxiety, which was mostly explained in the literature by the high number of hours dedicated to caregiving, the severity of stroke, and the degree of survivor's independence [10, 16, 76, 84–88]. Also, the existence of physical comorbidities among caregivers and survivors was indicated as predictors of poor QoL, emphasizing the need of health monitoring in order to optimize the health outcomes of both and consequently improve their QoL [16, 85, 89–92]. Thus, the development of strategies that help to prevent or alleviate adverse health effects of caregiving [16, 76, 84, 93, 94], as well as the promotion of coping and planning strategies [95–98], may increase caregivers' perceived health status, well-being, and survivors QoL, which were described as protective characteristics.

Unanimously and in line with most of the studies on general population, this scoping review showed that higher socioeconomic status of stroke survivors and informal caregivers, namely higher educational levels, more financial resources, and employment, was associated with caregivers' better perceptions of QoL. More educated individuals tend to present higher levels of knowledge about stroke and to more quickly and easily access to reliable information regarding care and support [99, 100], which may contribute to more effective management of health-related situations, as well as, to a quicker adaption to the caregiver role [101]. Similarly, individuals with higher income less frequently face vulnerable situations, namely lack of resources and opportunities, general uncertainty about future, and are less vulnerable to the variations of income, which positively influence their perceptions of QoL [102]. Furthermore, being employed has positive impacts on physical and mental health of both survivors and informal caregivers, since it contributes to meeting financial needs, maintaining family well-being and their role in society [103–105]. Therefore, public health and socioeconomic policies and practices should promote equitable access to information, education, training, support, and employment opportunities directed to stroke survivors and their informal caregivers. These strategies will improve inclusion, long-term support, and enhance awareness about stroke care, by anticipating, supplying needs and encouraging the best use of resources [104–107].

Caring for stroke survivors with physical, mental, and communication disabilities requires greater skills, availability, and a higher physical and emotional effort from informal caregivers, namely on the maintenance of Activities of Daily Living. These demands increase caregivers' fatigue, stress, and burden, which may trigger harmful consequences on different domains of QoL [108, 109]. Thus, post-stroke care services should adopt an inter-disciplinary approach to stroke care, including physical rehabilitation for improving survivors' disabilities and mental, educational, and social support directed to informal caregivers. The provision of stroke and care-related information, training, and emotional support will contribute to empower caregivers to provide quality care to survivors, without detriment of their health, by increasing their knowledge and skills and helping them to cope with the negative consequences of caregiving [90, 110–112].

In line with the results described in our study, previous research on the psychological effects of care supports that caregivers who spend more hours on caregiving present worse QoL, mainly due to higher levels of burden [113, 114], reduction of the free time available (e.g. for social activities, managing their own life and families) [115], and frequent loss of their jobs [116]. The perception of QoL of informal caregivers was also influenced by the instrumental support given to stroke survivors and informal caregivers, namely healthcare assistance. This suggest that preventing the burden and reducing the strains of caregiving are essential that health professionals and governmental support policies consider the care trajectory of each caregiver, trying to fill their main needs and promoting their QoL.

The results of this scoping review support the current literature stating that caregivers with more satisfactory relationships have better perceptions of QoL [117, 118]. Hence, health and social practices should consider the relational dynamics and needs throughout the care continuum, to promote caregivers' QoL. However, few studies have also addressed the association between contextual characteristics and informal caregivers' QoL, despite the current evidence supporting the importance of the social context on survivors' QoL after stroke [82, 119, 120]. The results from this scoping review seem to reinforce the positive influence of a more supportive social context on QoL, which may be explained by the alleviation of informal caregivers' psychological distress and the promotion of emotional support and companionship [121–124]. Considering that social context shapes survivors and caregivers needs, expectations, preferences and QoL, further health and social research, policies, and practices should consider its importance on preventing psychological health implications and providing favourable conditions for a life of quality.

## Limitations

Although our scoping review only included studies that reported as their main outcome the QoL of informal carers of stroke survivors, constructs such as life situation and well-being, HRQOL, and general health, have been used interchangeably in the studies as synonyms of QoL [125]. Such heterogeneous conceptualization of QoL may justify the high variability of instruments used as well as the contradictory results described across studies, hindering the comparability of findings. Additionally, the inclusion of studies carried out with populations from different countries and continents hampers the use of a population measure capable of compare all the QoL results. Also, the exclusion of studies who did not report scores on a 0–100 scale or mean values along with the standard deviations or the 95%CI in the forest plot is a limitation of the current study.

The scarcity of qualitative and mixed-methods studies jeopardizes an in-depth understanding of the characteristics influencing QoL, since some particular experiences, insights, and explanations can only be captured through these methodologies. Also, the poor variability in the countries where studies were performed, as well as the very restricted number of studies focusing on ethnicity, may influence the results and preclude the understanding of some specificities of caregivers' QoL. However, the selected databases, the search strategy, and the inclusion criteria were carefully structured and sustained on the literature and research experiences in order to capture the greatest amount and diversity of suitable studies for the goals of this scoping review.

## Conclusions

This scoping review identified some important gaps in the literature regarding the characteristics influencing the QoL of informal caregivers of stroke survivors. There is a need for standardizing the conceptualizations of QoL, and widely use of reliable and valid instruments sensitive to the idiosyncratic characteristics and needs of informal caregivers. As such, it is crucial to produce evidence to support public health and social centred among informal caregivers of stroke survivors.

Further research should clarify and understand the associations between QoL and sex, age, stroke classification, household composition, relationship with the survivor, and care trajectory, contributing to the identification of higher risk groups to develop early, targeted, and differentiated interventions and support. Similarly, the investment in mixed-methods designs will allow a deeper understanding of the characteristics influencing the QoL of informal caregivers, contributing to the design and development of health promotion strategies centred on citizen needs and experiences. Moreover, further cross-country and cultural research is essential in order to capture broader, diverse, and representative experiences, allowing comparisons and providing quality support to caregivers, adjusted to different realities, needs, and cultural backgrounds.

This review also calls to the need for health and social research, policies, and practices that consider the diversity and complexity of the characteristics influencing QoL of informal caregivers, especially physical and mental health of both survivors and caregivers, the stroke characteristics, the relationships and the social context, contributing to identify high risk groups, empower informal caregivers, and promote the main enablers for a better QoL.

**Author contributions** AM and FT reviewed the literature and identified the studies. AM, FT, and EA selected the studies. AM was responsible for the studies summary and drafted the manuscript. FT, MA, AH, and CN collaborated in analysis and interpretation of the data and reviewed the manuscript critically. EA designed the study, analysed, and interpreted the data, and reviewed the article critically for important intellectual content. All authors approved the final version of the manuscript.

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## Declarations

**Conflicts of interest** The authors declare that they have no competing interests.

**Research involving human and animal participants** This article does not contain any studies with human participants or animals performed by any of the authors.

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