Supplementary materials

Suppl. 1. Description of 21 included studies with findings in the form of domains/categories of needs of informal caregivers caring for stroke patients in the home environment

First author (year), country	Study aims	Caregiving time period	Caregivers' information	Type of survey	Type of analysis	Needs domains/categories
Bakas et al. (2016), USA	To identify patterns of expressed needs and interest in skill-building strategies and how these changed over the course of a TASK II intervention.	8 weeks after discharge, 8 weekly telephone sessions, with a booster session one month later.	123 stroke caregivers (female 78.1%) – spouses 48.0%, non-spouses 52.0% (adult children, adult children-in-law, other relatives, and significant others).	Randomized controlled clinical trial, the Caregiver Needs and Concerns Checklist (CNCC).	Descriptive analyses (frequencies).	35 perceived needs or concerns related to five main areas: (1) information about stroke (content about warning signs of another stroke, lifestyle changes, where to find resources, how to manage specific problems or complications, risk factors for stroke, and common medications), (2) managing survivor emotions and behaviors (survivors' feelings, personality changes, cognition, communication, and social activities), (3) providing physical care (medications, diet, exercise, mobility, and activities of daily living), (4) providing care (finances, legal healthcare issues, transportation, and respite care), and (5) caregivers' personal responses to caregiving (topics relating to the caregiver's emotions, energy level, social activities, and health, balancing other responsibilities and asking for help).
Batuecas-Caletrío and Rodríguez-Martín (2022), Spain	To understand the perceptions of a family unit coping with a stroke diagnosis.	Five years after a stroke.	A 69 year-old woman who had suffered a stroke and her husband (73 years) and son (39 years).	Qualitative research based on life-history, semi-structured interviews.	Constant comparative method and coding process.	(1) family dynamics (domestic tasks, roles), (2) individual (relationships, time, new priorities), (3) health physical (tiredness, headaches, muscle overload) and emotional (incredulity, irritability, anxiety, resignation), (4) health and social assistance (information, facilities, lacks), (5) emotional support (family, family members of other patients, professionals)
Cecil et al. (2013), UK	To explore caring and coping among caregivers of stroke survivors and identify factors that had an impact on their lives.	2008-2010, approximately 6 weeks following hospital discharge.	30 caregivers (23 female, 7 male) – 19 spouses, 7 adult children, 3 sisters, 1 other family relative.	Qualitative descriptive study, semi-structured interviews.	Content analysis.	Nine thematic categories, which fell into three broad categories: (1) the impact of the stroke event on the caregiver (changes to lifestyle, concerns and worries, mental health issues), (2) the extrinsic factors that support the caring scenario (health professionals, information and knowledge, family support), and (3) the intrinsic factors that help caregivers to cope with the new role (own health and well-being, gratitude and faith, the dyadic relationship).
Denham et al. (2019), Australia	To qualitatively explore the unmet needs of caregivers of stroke survivors, and their preferences for interventions and support services.	Participants had cared for a person who had experienced a stroke for an average of 5.7 years, and ranged from three weeks to 17 years of care.	24 caregivers of stroke survivors (19 female, 5 male) – 20 spouses, 2 partners, 2 others.	Semi-structured, qualitative interviews.	Inductive thematic analysis.	(1) social relationships and support, (2) obtain adequate information, (3) taking care of oneself, (4) accessing appropriate services.

Denham et al. (2020), Australia	To (1) identify the types of websites available to caregivers of stroke survivors who seek support or to connect online with other caregivers of stroke survivors, and (2) analyse the online content produced by caregivers of stroke survivors to identify their unmet needs.	October 2017, not specified.	896 posts produced by caregivers of stroke survivors.	Systematic review.	Content analysis.	2,124 unmet needs appeared in 896 posts from caregivers (1) Emotional and psychological (Help dealing with own emotional distress, Know how to provide emotional and/or psychological support for stroke survivor, Deal with uncertainty and life after stroke, Get emotional support for self/have someone to talk to, Find meaning (self or partner) (2) Impact on carer daily activities (Financial impact, Balance own needs with caregiving, Help looking after own mental and physical health, Deal with impact on work, Assistance with patient daily needs, Help from others to manage caregiving roles, Receiving support to deal with changes in identity, Impact on lifestyle and schedule, Know how to maintain a sense of control) (3) Comprehensive stroke care (Have a supportive relationship with healthcare professionals, Access to health services, Be told about the help healthcare providers can offer, Have possibilities to participate in the stroke survivors' care, Obtain the best possible care for stroke survivors, Co-ordination and continuity of physical and emotional care, Information provided by healthcare professionals was appropriate) (4) Relationship (Deal with changes in relationships with partner, Have a satisfactory relationship with others, Help communication with others, Have an intimate relationship with stroke survivor and consideration of sexual need, Help communicating with the stroke survivor about illness and his or her concerns) (5) Information (Knowing what to expect, The illness and management, Providing care to patient, Death and dying) (6) Spirituality (Feel there is hope for the future, Receive spiritual support).
Farahani et al. (2020), Iran	To determine the needs of family caregivers of older stroke patients.	4 stages: admission time, pre-discharge, two weeks and 12 weeks post-discharge.	200 family caregivers of older stroke patients.	Longitudinal study, caregivers' needs questionnaires.	Descriptive methods.	Health information, Community networks, Professional support, Instrumental support, Emotional support, Involvement with patient care.
Fugl-Meyer et al. (2019), Sweden	To explore long-term experiences of satisfaction with life in persons with stroke and spouses.	1 and 6 years after stroke.	24 spouses (88% female), mean age of 65 years.	Prospective cohort-study, structured interviews, tests and questionnaires.	Descriptive methods.	Closeness – Family life, Partner relationship, Sexual life.
Geard et al. (2020), Norway	To explore how family members of persons with ABI and SCI in the chronic phase make sense of and adjust to living with an altered life situation.	Minimum of 1.5 years post-injury.	6 family members – 4 spouses, 1 mother, 1 partner.	Qualitative research design, focus group interviews.	Systematic analytic frame of thematic analysis.	Two main themes were identified: (1) drawing upon different coping strategies (downplaying the consequences of injury; keeping a positive outlook; making comparisons to worst cases; finding strengths within; and taking control through meaningful behaviors, (2) balancing family needs against personal autonomy (in search of a balance, making room for own needs, being motivated through relationships, dealing with the necessary but upsetting need for professional assistance).

Holloway et al. (2019), UK	To explore how families are affected and integrates their views on the formal/informal support received as a consequence of ABI.	2–28 years after stroke.	16 family members (15 female, 1 male) – 7 mothers, 7 partners, 2 others.	Qualitative research design, semi-structured interviews.	Inductive thematic analysis.	Six themes were identified: (1) the existing context (sudden and unexpected events, pre-existing roles and context, (2) the all-encompassing challenge (dependency on family support, behaviors that challenge, the added burden of loss of insight, the unpredictability of the future, (3) loss and grief (family member loss of identity, complicated grief, questioning the value of life, (4) unavoidable duty (inescapable duty, fighting for services, personal sacrifice, (5) experiences of poor support (variable and poor quality of care in hospital, poor communication, poor professional knowledge and understanding, professionals who exclude family, (6) positive support and change (specialist knowledge, empathic understanding and humanity, practical help and 'presence', acknowledging uncertainty, flexible approach).
Kniepmann and Kerr (2018), USA	To identify partner perspectives and experiences related to intimacy and sexuality following a stroke.	At least 3 months passed since the onset of the partner or spouse's stroke.	9 partners or spouse (7 female, 2 male).	Qualitative approach, interviews.	Techniques of thematic analysis.	Four themes were identified: (1) maintaining closeness and togetherness, (2) redefining sexuality and intimacy after stroke, (3) coping with lack of resources, and (4) wishing health professionals would discuss these topics.
Kruithof et al. (2016), The Netherlands	(a) To determine levels of and factors explaining partners' burden, anxiety, and depressive symptoms at two months post-stroke, (b) to predict partners' burden, anxiety and depressive symptoms at one-year post-stroke based on patient and partner characteristics available at two months post-stroke.	2 months post-stroke.	183 partners of stroke patients (78.7% female).	Prospective cohort study, the Caregiver Strain Index and the Hospital Anxiety and Depression Scale.	Descriptive statistics.	Partner outcomes at two months post-stroke explained by several variables: partners' burden and emotional problems on the other outcomes (burden, anxiety, and depressive symptoms), partners' psychosocial factors (satisfaction with their relationship, proactive coping, self-efficacy and everyday social support).
Li et al. (2017), China	To investigate the needs and rights awareness of stroke survivors and caregivers in Tianjin, China.	June 2014 – February 2015, 1–10 years post-stroke.	212 family members (117 females, 95 males), mean age 52.6 years.	Cross-sectional, single-center questionnaire survey, interviews.	Descriptive methods.	The needs for timely diagnosis and treatment, financial support, social support.

López-Espuela et al. (2018), Spain	To explore and document the experiences and values of spouse caregivers of stroke survivors. To gain more in-depth knowledge of how the act of caring and the adaption process affects caregiving spouses.	June 2012 – January 2014, more than 6 months after discharge.	18 spouses (5 male, 13 female) – an average age of 55 years.	Phenomenological qualitative study, semi-structured, in-depth interviews.	Thematic content analysis.	Three major themes that emerged from participants narratives: (1) Intensity of caregiving, labelled "caregiving and that's all" (no life horizons, the caregiver's impossibility of moving away from the caring role), (2) Disruption in the couple, labelled "breaking the couple's life", and (3) Loneliness of caregiving, labelled "going through the transition alone".
Lu et al. (2022), China	To deductively explore the needs of family members caring for stroke survivors in China.	October 2014 – April 2015, at least 3 months post-stroke.	26 family caregivers (20 female, 6 male) – 21 spouse, 5 children, 1 daughter in law.	Semi-structured interviews, the Caregiver Task Inventory-25 (CTI-2(5) framework.	Deductive qualitative content analysis method	Learning to cope with new role, providing care according to care-receiver's needs, managing own emotional needs, appraising supportive resources, balancing caregiving needs and one's own needs, needs related to financial support.
Mumma (2020), USA	To describe losses experienced following a stroke as perceived by patients and their spouses.	At least 3 months post-stroke.	60 spouses, mean age of 65 years.	Exploratory cross-sectional survey, semi-structured interviews.	Content analysis.	Three major categories of loss: (1) activities (travelling, social life), (2) abilities and characteristics (communication), and (3) independence.
Pesantes et al. (2017), Peru	To characterize the impact of post-stroke care among informal caregivers in a setting of transitioning economy.	June–September 2013, at least 6-month post-stroke.	12 caregivers (8 females) – spouse or child, mean age 52.5 years.	Qualitative study, semi-structured interviews.	Thematic content analysis.	(1) Emotional impact of caregiving (depressive symptoms such as tiredness, sadness, extreme sensitivity, difficulty sleeping, lack of motivation and physical symptoms, e.g., headaches, suicidal ideation), (2) Stress factors affecting caregivers (the lack of independence and time to engage in social activities, e.g., going out with friends or visiting relatives), (3) financial needs, (4) the need to see a psychologist
Rahman et al. (2018), Malaysia	To determine the caregivers' burden and challenges as reported by caregivers of stroke survivors.	November 2015 – June 2016, follow-up at a conveniently selected community rehabilitation center.	18 caregivers (17 female, 1 male) – spouse (55.6%), children (22.3%), mean age 50.6 years.	Cross-sectional study, semi-structured interviews.	Qualitative data analysis.	Five categories of themes emerged: (1) Physical (Sleep disturbance, Forgetfulness and emotionally irritated), (2) Social (Lack of time with friends, Unable to attend family function), (3) Financial (Nutritional needs, Education, Transport), (4) Employment (Workplace), (5) Time (Multiple responsibilities, Lacking time for self).
Sidek et al. (2022), Malaysia	To investigate the experiences of the caregivers of stroke survivors and access to stroke care in Malaysia.	At least 3 months post-stroke.	10 informal caregivers (5 females, 5 males) – 5 children, 4 spouses, 1 sibling.	Phenomenological qualitative study, semi-structured, in-depth interviews.	Thematic content analysis.	Caregivers had two primary needs: (1) Educational and informational support (information about comprehensive stroke care at home), (2) Psychological support requirements and needs (psychological support to themselves).

Stiekema et al. (2020), The Netherlands	To identify the perceived needs of people with acquired brain injury and their partners.	October 2016 – May 2017, stroke occurred over six months ago.	Three partner focus groups, *n* = 19 (7 males, 12 females), mean age 60.2 years.	Focus groups, semi-structured topic guide.	Inductive content analysis.	Three themes covering an intrapersonal, social, health care and societal level: (1) Adaptation to changes (awareness of consequences, process of acceptance, dealing with consequences in daily life, personal time, role changes relationship/family), (2) Understanding from relatives/friends, professionals, institutions, and society, (3) Timely and individualized care (information, transition to home, searching for help and support, peer support, support for partner/family, case management).
Tiwari et al. (2021), India	To study the perceptions along with experiences of stroke survivors and caregivers, with a purposeful sampling design.	October 2014 – March 2015, 2 months after discharge from hospital.	12 family caregivers (9 females, 3 males) – spouse, daughter-in-law or child of the stroke survivor, mean age 32.5 years.	Qualitative cross-sectional study, in-depth interviews.	Framework analysis.	Major factors that increase the burden of the caregivers: dual responsibility, adjustment for self, job compromise, financial jeopardy, concern for future and family, diminished leisure time, hampered social life, long caring hours, immense burden, anxiety and strain.
Tsai et al. (2015), Taiwan	To explore the changing needs of family caregivers of stroke patients and factors related to the needs in four stages, before the transfer from intensive care unit to neurological unit, before discharge, 2 weeks post-hospitalization, and 3 months post-hospitalization.	2009–2010, four time points – at ICU, before discharge, 2 weeks post-hospitalization, and 3 months post-hospitalization.	60 family caregivers (25 males, 35 females) – children, spouse, daughter in-law, parents, siblings, grandchildren, mean age was 44 years.	Longitudinal research study, questionnaire.	Descriptive methods.	The greatest needs were for information on how to handle medical emergencies and what to do when the patient became upset or acted strange in the professional support domain; information about physical problems and medication and treatment in the health information domain; and conveying advice with the help of professionals in the community networks domain. At 2 weeks post-hospitalization around 88–95% of family caregivers had those needs. At 3 months post-hospitalization about 75–93% of family caregivers had those needs.