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Needs of stroke survivors as perceived by their caregivers: A scoping review

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Abstract

Objective—Caregivers usually are not involved while planning the stroke survivor's medical and rehabilitation goals and interventions. This review aimed to identify the needs of stroke survivors as perceived by their caregivers.

Design—A literature search from 2003 until 2014 was conducted using Medline, CINAHL, PsychINFO and Google Scholar. Sixty-six studies were included. Most studies excluded did not encompass caregivers' perspectives. Four reviewers screened the titles, abstracts, and full texts of the articles for inclusion. The data extracted from these studies were synthetized into meta-themes.

Results—Fifty-two qualitative, ten quantitative survey, and four mixed methods studies were included in the final synthesis. The studies came from eleven countries. The data synthesis produced three meta-themes: a) *body functional needs*, including psychological function, physical function, cognitive function, and uncertainty related to function; b*) activity and participatory needs,* including healthy lifestyle, physical activities, speech, independence, cognitive activities, and uncertainty related to activities and participation; and c) *environmental needs,* encompassing support, services, safety, accommodation and accessibility, and uncertainty related to environmental factors.

Conclusion—This scoping review identified a range of needs of stroke survivors as perceived by their caregivers. Incorporating the caregiver's preference and values into clinical decisions may improve outcomes among stroke survivors.

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Conflicts of Interest

The authors declare that no conflicts exist in connection with this paper. Preliminary results were presented at the Academy Health Scientific Meeting, Minneapolis, Minnesota, June 2015; the Gerontological Society of America's Annual Scientific Meeting in Orlando, Florida, November 2015; and the Topics of Patient Centered Outcomes Research, UTMB, Galveston TX, February 2016.

Keywords

caregivers; rehabilitation; perspectives; patient-centered care; stroke; unmet needs

Introduction

Nearly 750,000 people are affected by new or recurrent stroke annually in the United States.[1] These individuals often have complex needs that may include physical, cognitive, psychological emotional, and socioeconomic factors.[2] Regardless of the severity of injury and age, most people experience diminished quality of life following the event, impacting their activities of daily living, relationship with their family members, and social lives.[3]

Informal caregivers help support and improve stroke survivors' medical and rehabilitation outcomes. Approximately 3.5 million individuals with stroke receive care from others, including family, friends, and paid caregivers.[4, 5] Among family members caring for individuals with stroke, spouses and children are often the primary caregivers.[5] The sudden onset of stroke and consequential uncertainty increases caregiver burden and anxiety,[6] as they undertake new roles and responsibilities not only for themselves but also for the stroke survivors.[7] Mood and behavior changes in caregivers may affect the outcomes for stroke survivors.[8] Considering the multidimensional recovery and rehabilitation process following stroke, it is essential to understand the needs and health care outcomes of stroke survivors as perceived by the caregivers and involve them in the decision making process.[9]

The Patient-Centered Outcomes Research Institute has identified the importance to inquire needs of stroke survivors as perceived by their caregivers, while making health care decisions [10] Thus recognizing, supporting, and involving the caregivers in the stroke survivors care can help improve survivors' health outcomes. In addition, involving the caregivers enhances their experiences with health care, and also reduces the associated expenditures.[11] Caregivers often provide a unique perspective as they are constantly involved in the stroke survivors' care. For instance, a patient with a complicated health condition along with cognitive decline may be unable to participate fully in his care.[12] Engaging caregivers in the decision-making process can supplement the patient-centered perspectives, which can further improve the appropriateness of prescribed clinical and rehabilitation interventions, and diagnostic tests.[12]

The needs of stroke survivors perceived by the caregivers are not usually included during the post-acute discharge planning,[13] because of inadequate time, and availability of resources.[14] The health care professionals (HCPs) must gauge a way to include the caregiver as a part of the care team. To address this issue, a scoping review was conducted to provide an overview of the needs of stroke survivors as perceived by their caregivers during the different phases post-stroke. A scoping review allows the presentation of the range of available evidence on a broad topic, or identifies the gaps in existing literature.[15, 16] The purpose of this scoping review was to identify and synthetize the needs of stroke survivors as perceived by their caregivers by performing a secondary analyses of the studies included.

Methods

This study conforms to all PRISMA guidelines, and reports the required information accordingly (see Supplementary Checklist).

Search strategy

A medical librarian searched four electronic databases: Medline, CINAHL, PsycINFO, and Google Scholar from 2003 until 2014. The search included the following main keywords in various combinations: “stroke”, “survivors”, “cerebrovascular accident”, “convalescence”, “rehabilitation”, “psychology”, “post-stroke”, “ recovery”, “patient”, “caregiver”, “client”, “consumer”, “family”, “needs”, “hope”, “goals”, “goal attainment”, “objective”, “preferences”, “expectations”, “anticipation”, “attitudes”, “satisfaction”, “content”, “discontent”, “participation observation”, “decision making”, “shared decision making”, “participation”, “engagement”, “involvement”, “empowerment”, “perception”, “quality of life”, “aftercare”, “treatment outcomes”, “motivation”, “achievement”, “intention”, “drive”, “incentive”, “disincentive”, “discharge planning”, “attitude to health”, “psychology”, “recovery of function”, “outcome measures”, and “outcome assessment”. The reference lists were hand searched for relevant studies (See Search Strategy Supplemental Digital Content file).

Studies included were original peer-reviewed articles in English, addressing needs of stroke survivors throughout the survivors’ recovery process in all settings (acute, post-acute, or community) as perceived by the caregiver. The focus of this review was to explore needs of stroke survivors as perceived by the caregivers; hence, all studies included were those that explored this perspective. Studies excluded were those with only stroke survivors’ perspectives, did not distinguish caregivers’ perspectives from those of other stakeholders, did not distinguish stroke from other conditions, focused only on perspectives for a program/ intervention evaluation. Although some studies included caregivers own needs or other stakeholders’ perspectives, the data extraction for this review only focused on the needs of stroke survivors perceived by their caregivers. Case studies, dissertation theses, editorials, reviews, and commentaries were also excluded.

Three reviewers independently screened the titles and abstracts (SK, MS, and AK) for inclusion. A fourth reviewer (TR) provided consensus in case of disagreement. Two reviewers (SK, MS) independently screened all full-text articles. The Kappa calculated for a subset of abstracts (n=171), and full text articles (n=50) was 0.74 and 0.73, respectively. Major subsets of full text articles (80%) were re-screened by an additional reviewer (AK) to ensure quality control.

Appraisal of selected studies

The quality of the included studies was evaluated using the Critical Appraisal Skills Programme (CASP)[17] for qualitative studies, Critical Appraisal of a Survey by the Center for Evidence-Based Management (CEBMa)[18] for surveys, and the Mixed Method Appraisal Tool (MMAT)[19] for mixed-methods studies. Two reviewers (SK and MS) independently evaluated the quality of each article. Appraisal agreement between reviewers for a subset of the retained studies (n=39) was measured with Kappa: CASP=0.63, CEBMa =0.76, and MMAT=0.52. The low Kappa score for MMAT was a result of only four studies with mixed methods being included in the review. Disagreements were resolved through discussion with the additional reviewer (TR). Studies were not excluded based on quality, as the characteristics required to report the quality of research are not consistent.[20]

Data extraction

Characteristics of selected studies such as demographics including age and gender of caregivers, sample size, purpose of the study, setting and time point, and methodology were extracted by one reviewer (SK) and checked for accuracy by two reviewers (MS and TR). A codebook defining the themes and subthemes was created using NVivo.[a] Subthemes to discover caregivers' perspectives emerging from the results of the full-text articles were identified using an inductive approach with line-by-line coding.[21] To identify the themes, a balance between *emic* and *etic* approaches was sought.[22] Two coders (SK and MS) read all articles independently, and sorted quotations from each article into relevant themes and subthemes. Techniques used to identify the themes included repetition, indigenous typologies, similarities and differences, and systematically comparing across the data extracted from different studies.[21] At the early stages of analysis, all possible themes were identified; the consolidation of themes was done later. Consensus on each independently identified theme or subtheme was achieved through discussion. In case of disagreement, TR resolved differences via discussion. To ensure quality control, an additional reviewer (MP) independently re-coded the themes of family support and uncertainty. Kappa for these two themes was 0.60. In addition, the quotations under all themes and subthemes were reviewed by MP to ensure quality control. Having multiple coders maximized the likelihood of identifying all possible themes and minimized any bias during theme identification.[21] The themes and subthemes were refined by grouping the related topics by SK and MP. During this process, some themes and subthemes were merged, separated, or relabeled.

Results

The search strategy is shown in Figure 1. The 66 included full texts involved a combination of 1,926 caregivers along with other stakeholders such as stroke survivors, health care professionals (HCPs), and managers. Out of the 66 full texts included in the final review, 39 studies focused only on the caregivers' perspectives, 23 studies focused on the perspectives of both stroke survivors and caregivers, two studies included the perspectives of caregivers and HCPs, and two studies identified the perspectives of stroke survivors, caregivers, and HCPs. Table 1 summarizes characteristics of the 66 articles. Fifty-two were qualitative, [4, 7, 9, 23–71] ten utilized a survey, [72–81] and four used a mixed methods approach.[82–85] Most of the studies (n=45, 68%) were conducted in the community.

Appraisal of selected studies

Of the 52 qualitative studies appraised using CASP, all had a clear statement of the research aim, appropriately used qualitative methodology, presented clear findings, and mentioned

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[a] NVivo 10 for Windows, QSR International.

the value of their study. Almost all studies reported the data collection process. Thirty studies provided the rationale for their research design,[9, 11, 23, 25–27, 29, 31–33, 35, 39, 41, 42, 44–50, 52–54, 58, 62, 65, 66, 70, 71] nine discussed the relationship between researcher and participants,[29, 42, 44, 46, 50, 54, 66, 70, 71] 37 reported rigorous data analyses procedures,[4, 7, 9, 11, 24, 26–28, 30–37, 39, 41–46, 48–50, 52–54, 58, 60, 63, 65, 67–70] 45 reported the ethical considerations,[4, 7, 9, 23–25, 27–29, 31, 32, 34, 36–50, 52–60, 62–66, 68–71] and 49 reported the recruitment strategy.[7, 9, 11, 23–25, 27–32, 34–63, 65–71] Of the 10 quantitative studies appraised using CEBMa, all clearly addressed the research question, methods, selection of participants, and had a sample representing the population. None of the studies assessed the sample size *a priori* or reported confidence intervals. Seven studies achieved a response rate above 60%, [72, 74–76, 78, 79, 81] six utilized reliable and valid measurements,[74, 77–81] and seven assessed statistical significance.[72, 74, 76–80] All mixed-methods studies appraised using MMAT used the methodology appropriately, used relevant sources to collect the qualitative and quantitative data, and had sample representing the population. Although the integration of qualitative and quantitative approaches was relevant for three studies, [82, 83, 85] none of the studies discussed the limitations of integrating qualitative and quantitative studies. For the qualitative section of MMAT, none of the studies mentioned the researchers' influence with the participants or the transferability of findings. For the quantitative section of MMAT, three studies had a response rate above 60%,[82, 84, 85] and two used valid and reliable instruments.[84, 85]

Data synthesis

The subthemes were aggregated under three meta-themes using the International Classification of Functioning, Disability and Health (ICF)[86] model, specifically utilizing the ICF Core Sets of Stroke framework. [87] Table 2 reflects the *body functional needs*, where the caregivers mentioned only functional needs for the stroke survivor and did not mention any structural need. Table 3 reflects the *activity and participatory needs*, and Table 4 lists the *environmental needs*. The stroke survivor needs in each table are listed in the order of most common need reported by the caregivers in the literature. The stage of care for each need is listed in respective tables as well. Most of the stroke survivor needs were identified in the community, following discharge from acute care and rehabilitation. The subthemes under each meta-themes are listed below.

Body functional needs, Table 2—Caregivers in 41 studies (62%) revealed the need for body functional needs following stroke. The most common *body functional needs* included, psychosocial function (n=26, 39%), followed by physical function (n=15, 23%), cognitive function (n=10, 15%) and uncertainty related to functional impairments (n=9, 14%).

Under the *psychosocial* function subtheme, ten articles mentioned the need to improve the mood of the survivor, and nine studies heighted the changes in behavior including anger, agitation etc. Caregivers in seven studies highlighted the importance of dealing with depression. The need to motivate and encourage the stroke survivor was emphasized in ten studies. Under the *physical function* subtheme, six articles highlighted that the caregivers were concerned for the overall physical function, and caregiver in one study specified the need to improve limb function. Caregivers in six studies also identified the importance of managing pain and fatigue. In addition, two studies emphasized the need for visual and hearing function, and four studies revealed the need to improve the voice functions. Under the *cognitive function* subtheme, ten articles revealed the need to improve the stroke survivors' cognitive function including, comprehension, memory, orientation, etc. Under the *uncertainty related to functional impairments* subtheme, caregivers in nine studies were uncertain of the stroke recovery process because of functional changes in the stroke survivor's body.

Activity and participatory needs, Table 3—Caregivers in 43 studies (65%) highlighted the activity and participatory needs for stroke survivors. The most common *activity and participatory need* included, healthy lifestyle (n=26, 39%), followed by physical activities and independence (n=15, 23% each), speech (n=11, 17%), cognitive activities and uncertainty related to limitations in activity and participation (n=2, 3% each).

Under the *healthy lifestyle* subtheme, the caregivers in 11 studies valued stroke survivors' social and leisure activities. Seven studies indicated the need to improve nutrition among stroke survivors. Caregivers were concerned with the overall health, including spiritual health of the stroke survivor in four studies and they highlighted the need to prevent future strokes in 13 studies. Under the *physical activities* subtheme, ten studies indicated the caregivers' perspectives related to self-care needs. Caregivers wanted to improve the mobility of the stroke survivors, and wanted them to walk, transfer independently, improve their balance and posture, increase physical activity, and independently climb stairs. Under the *speech* subtheme, in 11 studies the caregivers highlighted the need for the stroke survivor to communicate, express, and speak efficiently. Under the *independence* subtheme, 11 articles identified the need for the stroke survivor to return to normalcy and pre-stroke activities. Most of the caregivers wanted to preserve the survivor's autonomy, and wanted them to go back to work, and be able to drive. Under the *cognitive activities* subtheme, caregivers in two studies wanted to improve the stroke survivor's decision making and judgement. In addition, caregivers in two studies expressed *uncertainty* to plan for the future because of the survivor's limitations in activities.

Environmental needs, Table 4—In most of the studies (62 studies, 92% of the studies), the caregivers stressed the importance of some form of *environmental need*. The most common *environmental needs* included, support (n=50, 76%), followed by services (n=44, 67%), safety (n=17, 26%), accessibility and accommodation (n=14, 21%), and uncertainty related to environmental factors (n=11, 17%).

Under the *support* subtheme, 32 articles indicated a need for communication with HCPs, 27 studies highlighted the importance of support from family and friends. Nineteen studies indicated that the caregivers had difficulty paying for the survivors' medical bills, rehabilitation services, and other household expenditures, and four studies highlighted the need for support groups. Some supportive needs would benefit both stroke survivors and caregivers, but in some of the original texts, it was not possible to distinguish between needs of survivors and caregivers. Under the *services* subtheme, 28 articles indicated the need for rehabilitation services. The details on specifics of rehabilitation needs is listed in Table 4.

Twenty-nine studies revealed the need for information on various aspects for the stroke survivor. The specific information needs are listed in Table 4. Fourteen studies highlighted the importance of other supportive services including but not limited to having paid caregivers, meals etc. Under the *safety* subtheme, caregivers ensured survivors' safety to prevent falls in 12 studies because of impaired cognition,[40] restricted mobility,[49] lack of sleep,[4] inadequate support,[4] etc. In nine studies, caregivers were worried about leaving the survivor alone, and in four studies the caregivers wanted to safely administer these medications to avoid any mistakes. Under the *accessibility and accommodation* subtheme, six studies highlighted the need for accessibility at public toilets, travel and transportation. In addition, six studies revealed the need for equipment and other assistive devices for stroke survivors such as wheelchairs, walking frames, and augmented or alternative communications; and four studies highlighted the need for home and vehicle accommodation. Under the *uncertainty related to environmental factors* subtheme, the caregivers in 11 studies were unable to anticipate the stroke survivor's needs at home and community post-discharge.

Discussion

The current scoping review synthetizes the needs of stroke survivors as perceived by their caregivers. Researchers may have focused their inquiry only on a specific aspect of the recovery experience; hence, many may not have elicited all aspects of concern or their relative importance. Thus, the goal of this review was to provide a comprehensive listing of all needs mentioned, rather than attempting to interpret the relative importance of concerns. The synthesis revealed the outcome preferences under three meta-themes: *body functional needs*, *activity and participatory needs,* and *environmental* needs. The subthemes under these meta-themes align with the International Classification of Functioning, Disability and Health (ICF) model.[86, 87] The overview of the needs of stroke survivors as perceived by their caregivers provides clinicians with a framework for involving the caregivers during various stages of care. It was not clear from most of the studies if the needs of stroke survivors perceived by the caregivers were met or not; however, based on the secondary analyses of the texts, these are continuing or incompletely met needs.

The environmental needs were the most common need for the stroke survivor. In addition, most of these stroke survivor needs were identified by their caregivers when the survivor was in the community following discharge from acute care or rehabilitation. It is therefore important to include the stroke survivors needs during initial stages of care itself. Individuals with unmet needs usually have decreased satisfaction with health care services.[88] Lack of support from family and friends has been previously associated with poorer health outcomes including increased institutionalization among stroke survivors.[89] Also, lack of information on the stroke recovery process is associated with increased anxiety, stress, fear, and uncertainty about the future.[90] Around 47% of survivors fall at least once following stroke,[91] hence; caregivers are unlikely to leave the survivors alone unless they are in a safe environment with adequate accomodations.[92] Environmental barriers such as lack of accommodation, accessibility, need for assistive devices impacts safety of the stroke survivors to move independently.[93]

Clinical practice implications

An increased rate of post-stroke disability interferes with the individual's ability to perform activities of daily living. Since older stroke survivors have higher levels of inactivity,[94] caregivers in this review wished to improve stroke survivors' *independence* under the *activity and participatory needs* theme. The caregivers were also concerned with stroke survivors' *speech*. Stroke survivors with aphasia usually have difficulty interacting with their caregivers and their clinicians effectively, which puts them at risk of receiving inadequate health care.[88] In addition to motor and sensory activities, the clinicians should encourage the survivors to participate in social and leisure activities. The caregivers also valued the importance of stroke survivors' *social and leisure activities* under the *activity and participatory needs* theme, as the stroke survivors are at a higher risk of inactivity and feel isolated.[94]

The findings of this review suggest that the caregivers wished for increased *support and services* including under the *environmental needs* theme. Effective *communication with the patients helps the health care professionals* arrive at an accurate diagnosis, develop optimal treatment plans, and encourage participation in rehabilitation, which enhances patients' and families' satisfaction with overall care. In addition, lack of support from family and friends is known to be associated with poorer health outcomes among stroke survivors.[89] Being involved in support groups and services, and having additional assistance from paid caregivers is known to reduce stroke survivors' institutionalization.[89] This additional support makes the caregivers return to their caregiving duties with enthusiasm.[95] Health care professionals must educate the stroke survivors and their caregivers on the locally and regionally available community services. In addition, the provision of community-based services would help facilitate access to supportive services to address the long-term post-stroke needs of stroke survivors and their caregivers. The caregivers face increasing *financial* and economic burden post-stroke which may be due to the direct costs of medical expenditures, and the indirect costs of loss of productivity.[96] Identifying cost-effective interventions tailored to the individual stroke survivor and his/her caregiver can be cost-effective and yield positive outcomes.

In this review under the *service needs* subtheme, the caregivers identified the importance of *information and education* focused on stroke survivors' disease process, prognosis, interventions, and recovery. To maximize the stroke survivors' rehabilitation process, the caregivers must be informed on the various aspects of recovery, the disease process, and prevention of secondary complications. Lack of education on the stroke recovery process is known to be associated with increased anxiety, stress, fear, and uncertainty about the future.[90] Conversely, educating caregivers on the management of stroke improves health outcomes.[89] Providing stroke education may be one way to eliminate caregivers' feelings of uncertainty post-stroke. When communicating with stroke survivors and their families, clinicians should set realistic expectations and provide encouragement in working together on patient recovery. Maintaining a routine, and incorporating the caregivers' preferences can enhance stroke survivors' outcomes. The HCPs must educate the caregivers that the survivors' future may not be predictable, and work with them as a team through the recovery process.

In this review under the *environmental needs* theme, the caregivers were concerned with stroke survivors' *safety* and wanted to *prevent falls,* and *administer medications appropriately.* Caregivers were concerned with the stroke survivors' medication administration, fearing the adverse consequences of improper administration.[97] Engaging the caregivers during the stroke survivors' recovery process, educating them on the intrinsic as well as the extrinsic factors related to falls, and the adverse side effects of medications can improve the survivors' outcomes as their caregivers learn to manage these problems effectively.

The caregivers in this review also identified the importance of *accessibility, accommodations*, and *assistive devices* under the *environmental needs* subtheme. The increasing need for accommodation following deficits post-stroke includes a necessity for mobility devices such as canes, walkers, wheelchairs, and safety devices. The use of assistive devices, and appropriate accommodations are known to decrease caregiver burden and maximize the survivors' independence.[93] Most stroke survivors do not have adequate access to assistive devices and accommodations in spite of the associated benefits. The HCP's must prescribe assistive technology when appropriate.

Future research directions

Although poorer health care outcomes have been associated with ethnic minorities, [98] none of the studies in this review compared the perspectives of caregivers from different racial/ethnic backgrounds; which future studies must accomplish. The outcome preferences differs among patients, caregivers, and clinicians and across rehabilitation settings;[99] none of these studies compared the caregivers outcome preferences across post-acute settings. Information, rehabilitation, and heath care needs may vary at different time points of recovery; future studies must investigate the caregivers' perceived needs by various type of stroke (ischemic, hemorrhagic, and transient ischemic attack) and across settings (acute hospitalization, inpatient rehabilitation, skilled nursing rehabilitation, and community). Future studies/reviews must also focus the physical and emotional needs of caregivers themselves.

This review has some limitations. First, the influence of culture on preferred outcomes (e.g., the expectations of caregivers from Asian countries) was not assessed. Many qualitative and mixed methods studies did not comply with the quality measurement tools. Since the goal of the study was to encompass all the caregivers' perspectives of stroke survivors' needs, studies were included regardless of quality or country of origin. The review included the perceived needs of caregivers found using four databases, and did not include gray literature. Most of the studies included in this review did not distinguish between unmet, partially met, and met needs. However, we can assume that since the caregivers mentioned the importance of these needs for the stroke survivor, they may not have been completely met during hospitalization or rehabilitation. In spite of these limitations, this review had several strengths. A multidisciplinary group including physical and occupational therapists, psychologist, and sociologist interpreted the results from the included studies. In addition, as this was an interpretative review rather than an integration of the results, the synthesis can be transferred to similar population and settings.

Conclusion

This scoping review provides an overview of the needs of stroke survivors as perceived by their caregivers. The caregivers' perspectives of stroke survivors' needs were summarized under three domains that included *body functional needs*, *activity and participatory needs*, and *environmental* needs. This review underscores the important role of caregivers in the care and outcomes of stroke survivors. The findings of this review indicate that the caregivers recognized various needs for the stroke survivors, which may or may not have been met throughout their various phases of recovery continuum. Stroke survivors' needs as perceived by the caregivers must be included in rehabilitation along with the survivors' and clinicians' perspective to maximize their recovery by regaining independence.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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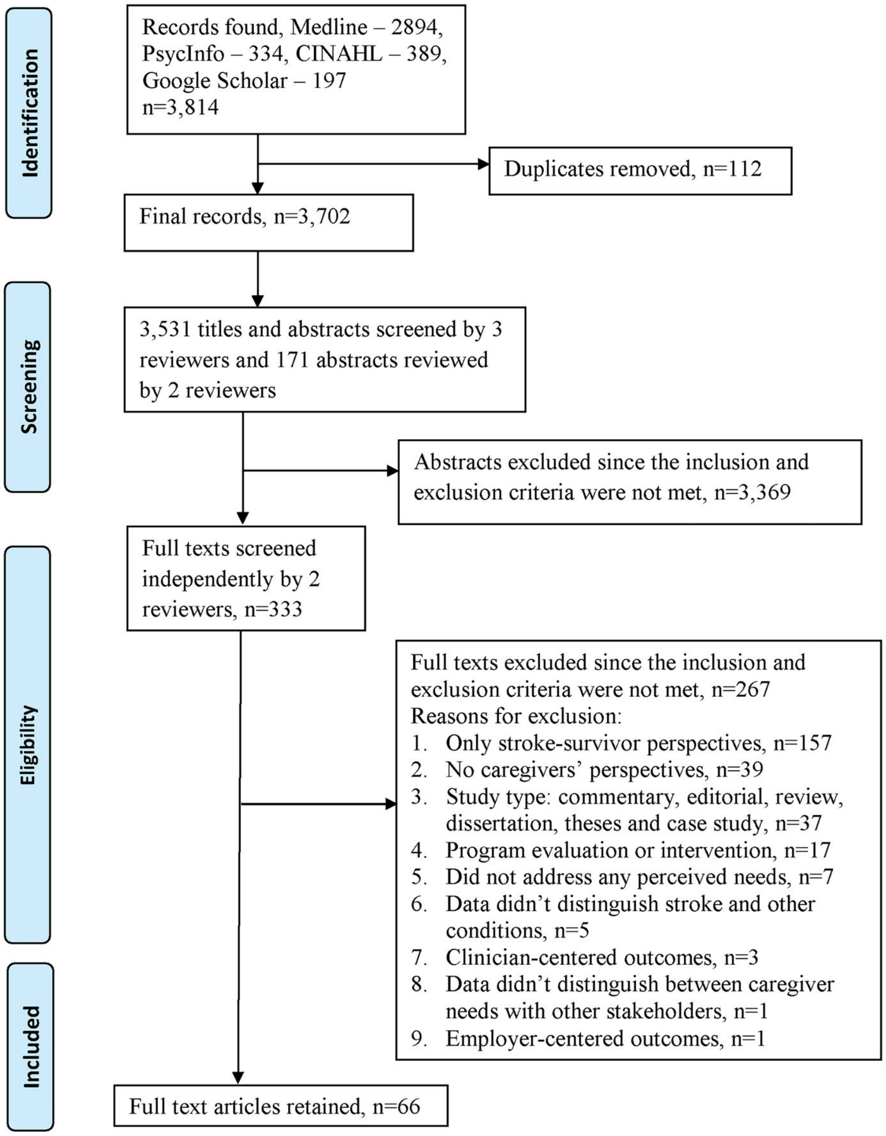

Figure 1.

Screening process of selected studies

Table 1

Summary and characteristics of studies included in the review (n=66)

Author	Purpose	Sample size	Caregiver characteristics	Setting and time point	Methodology	Data Collection
Backstrom, 2007 – Sweden[70]	Illuminate meanings in the lived experience of being a middle-aged close relative of a person who has suffered a stroke 1 month after discharge from a medical rehabilitation clinic	10 Caregivers	Age: 56 (40–64) Gender: F=8 Relationship: Partner=7, mother=2, other=1	Setting: Home/ Community Time point: 20w post stroke (12–33w), 1m post discharge from rehabilitation clinic	Phenomenology - hermeneutic	Interviews
Backstrom, 2009 – Sweden[24]	Illuminate the experience of being a middle-aged close relative of a person with stroke; 1 year post-discharge	9 Caregivers	Age: Median 55 (41–65) Gender: F=7 Relationship: Partner=7, parent =2	Setting: Home/ Community Time after stroke: 1m and 6m post-discharge	Latent CA	Narrative interviews
Backstrom, 2010 – Sweden[23]	Illuminate the meanings of middle-aged female spouses' lived experience of their relationship with a partner with stroke, during the first year post-discharge	4 Caregivers	Age:52 (40–58) Gender: F=4 Relationship: Partner =4	Setting: Home/ Community Time point: 1m, 6m and 12m post-discharge from rehab clinic	Phenomenology- hermeneutic	Open-ended narrative interviews
Boter, 2004 – The Netherlands [72]	Describe the number and types of problems mentioned by home-dwelling stroke patients and their carers, and nursing interventions applied	118 Caregivers 166 SSs Total=284	Age: 57 Gender: F=69 Relationship: Spouse/ partner=88	Setting: Home/ Community Time point: 1–4w, 4–8w, 10–14w, 18–24w post-discharge	Cochran's Q and Friedman test	Survey – telephone, home visit
Brittain, 2007 – UK[25]	Explore the notion of the bounded body and dirty work in light of the role of informal carers looking after someone with incontinence	20 Caregivers	Age: 51–86 Gender: F=13 Relationship: Partner, children	Setting: Home/ Community Time point: NR	Constant comparative, deviant case analysis	Structured interview
Brown, 2011 – NR[26]	Explore perspectives of family members of individuals with aphasia,	24 Caregivers	Age: 62 (40–87) Gender: F=15	Setting: Home/ Community	Interpretative phenomenology	Semi structured interviews

Author	Purpose	Sample size	Caregiver characteristics	Setting and time point	Methodology	Data Collection
	the meaning of living successfully with aphasia		Relationship: Partner=19, children=1, parent=3, sibling=1	Time point: ≥2y post-stroke		
Cameron, 2013 – Canada[27]	Support needs over time from the perspective of caregivers, perspective of HCPs, compare and contrast caregivers' and HCPs' perspectives	24 Caregivers 14 HCPs Total=38	Age: 66 (36–77) Gender: F=17 Relationship: Spouse=18, children=6	Setting: Rehabilitation, Home/ Community Time point: 1m-11y post-stroke	FW	Structured, in-person, telephone interviews
Cecil, 2013 – UK[28]	Caring and coping among carers of stroke survivors and identify factors that had an impact on their lives	30 Caregivers	Age: 36–84 Gender: F=23 Relationship: Spouse=19, children=7, sibling=3, other=1	Setting: Home/ Community Time point: 6w post-discharge	NR	Semi-structured interviews
Chang, 2013 – Taiwan[29]	Examine the institutional contexts that contribute to the low priority given to the development of self-care independence in a rehabilitation ward	12 Caregivers 15 HCPs Total=27	Age: NR Gender: NR Relationship: NR	Setting: Rehabilitation Time point: NR	Ethnography	Participant observation, interviews
Chow, 2014 – Hong Kong[30]	Experiences of family caregivers in caring for community-dwelling strokes survivors, services that help or do not help the caregivers in managing their role	29 Caregivers	Age: 42–87 Gender: F=21 Relationship: Spouse=17, children=12	Setting: Home/ Community Time point: 1->6 y post-stroke	CA	FG
Cobley, 2013 – UK[31]	Patients' and carers' experiences of Early Supported Discharge (ESD) services and inform future ESD service development and provision	15 Caregivers 27 SSs Total=42	Age: 73 Gender: F=13 Relationship: Spouse=15	Setting: Home/ Community Time after stroke: 14 d post-stroke	TA	Semi-structured interviews
Coombs, 2007 – Canada[71]	Examine the experiences of spousal caregivers for stroke survivors	8 Caregivers	Age: 66 (57–81) Gender: F=8 Relationship: Partner=8	Setting: Home/ Community Time point: 1y post-stroke	Phenomenology	Semi-structured interviews
Danzl, 2013 – USA[32]	Experience of stroke for survivors and their caregivers	12 Caregivers 13 SSs Total=25	Age: 56 (38–75) Gender: F=7 Relationship: Spouse=6, children=6	Setting: Hospital, Rehabilitation, Home/ Community Time point: 1–14y post-stroke	CA	Semi-structured interviews

Author	Purpose	Sample size	Caregiver characteristics	Setting and time point	Methodology	Data Collection
Dietz, 2013 – USA[33]	Social role changes experienced by PWA, understand communication strategies to reclaim previous social roles, and determine discrepancies between PWA and their potential proxies regarding social role changes	6 Caregivers 3 SSs Total=9	Age: 56 (39–88) Gender: F= 4 Relationship: Spouse=3, parent =1, children=1, other=1	Setting: Home/ Community Time point: 2–15y post-stroke	Phenomenology	Semi-structured interviews
Eames, 2010, – Australia[34]	Identify patients' and carers' perceived barriers to accessing and understanding information about stroke	18 Caregivers 34 SSs Total=52	Age: 60 (26–77) Gender: F=13 Relationship: Spouse=17, other=1	Setting: Hospital, Home/ Community Time point: 1w prior discharge, 3m post-discharge	CA	Semi-structured interviews
Egbert, 2006 – USA[35]	Communicative processes by which social support to assist right-hemisphere stroke survivors in the process of community integration	13 Caregivers 12 SSs Total=25	Age: 60 Gender: F=11 Relationship: NR	Setting: Home/ Community Time point: 6m post discharge	GT	Open ended interviews
El Masry, 2013 – Australia[36]	Psychosocial experiences and needs of caregivers	20 Caregivers 10 SSs Total=30	Age: 56 (31–90) Gender: F=16 Relationship: Spouse=15, children=2, sibling=3	Setting: Hospital, Rehabilitation Time point: >3m post-stroke	Interpretative phenomenology	Semi-structured interviews
Ellis-Hill, 2009 – NR[37]	Understanding on what constitutes a 'good' or 'poor' experience in relation to the transition from hospital to home following a stroke	13 Caregivers 20 SS Total=32	Age: NR Gender: NR Relationship: Spouse=10, children=3	Setting: Home/ Community Time point: Up to 3y post-stroke at 2w post-acute care discharge	FA	Semi-structured interviews
Garrett, 2005 – NR[38]	Information needs of patients and carers at different intervals post stroke	NR Caregivers NR SSs Total=16	Age: NR Gender: NR Relationship: NR	Setting: Hospital, Rehabilitation, Home/ Community Time point: NR	Modified GT	Open ended interviews
Gosman, 2012 – Sweden[39]	Older women experiences of life situation and formal support as carers of their partners after stroke	16 Caregivers	Age: Median 74 (67–83) Gender: F=16 Relationship: Partner=16	Setting: Home/ Community	NR	FG

Author	Purpose	Sample size	Caregiver characteristics	Setting and time point	Methodology	Data Collection
				Time point: NR		
Grant, 2004 – USA[7]	Problems and associated feelings experienced by family caregivers of stroke survivors during the 1st month after returning home	22 Caregivers	Age: 42–70 Gender: F=21 Relationship: Spouses = 9, daughter = 9	Setting: Home/ Community Time point: 1m post-discharge	CA	Telephonic interviews
Grant, 2006 – USA[40]	Problems and associated feelings experienced by family caregivers of stroke survivors during the 2nd and 3rd month after discharge from rehabilitation facility to home	22 Caregivers	Age: 56 Gender: F=21 Relationship: Spouse=9, children=9, others=4	Setting: Home/ Community Time point: 1w post-discharge	CA	Telephonic interviews
Green, 2009 – Canada[9]	Explore male patients with minor stroke and their wife-caregivers' perceptions of factors affecting quality of life and caregiver strain encountered during the first year post-discharge	26 Caregivers 26 SSs Total=52	Age: Mean 59 (33–75) Gender: F=26 Relationship: Spouse=26	Setting: Home/ Community Time point: >12m post-stroke at 1,2,3,6,9, and 12m post-discharge	CA	Semi-structured, telephone interviews
Greenwood, 2010 – UK[41]	Investigate the experiences of informal carers of stroke survivors from discharge to 3 months later	31 Caregivers	Age: 40–65 Gender: F=22 Relationship: Spouse=16, children=13, other=2	Setting: Hospital, Rehabilitation, Home/ Community Time point: before discharge, 1m, and 3m post-discharge	Ethnography	Open-ended interviews
Greenwood, 2009 – UK[42]	Investigate the experiences of informal carers of stroke survivors over time	31 Caregivers	Age: >65 y =23, <65y = 8 Gender: F = 22 Relationship: Spouse=16, children=13, other=2	Setting: Rehabilitation, Home/ Community Time point: close to discharge, 1m and 3m post-discharge	Ethnography	Open-ended interviews
Gustafsson, 2013 – Australia[43]	Enhance understanding of the transition experience for clients with stroke and their carers during	5 Caregivers 5 SSs Total=10	Age: 57 (37 - 51) Gender: F=3 Relationship: Spouse=3, children=1, other:1	Setting: Home/ Community Time point: 1m post-	Inductive TA	Semi-structured interview

Author	Purpose	Sample size	Caregiver characteristics	Setting and time point	Methodology	Data Collection
	discharge and the first month at home			discharge from rehab		
Haley, 2009 – USA[81]	Prevalence and stressfulness of stroke-related problems, perceived benefits of caregiving	75 Caregivers	Age: 64 Gender: F=59 Relationship: Spouse=40, children=23	Setting: Home/ Community Time point: 8–12 m post-stroke	Descriptive	Survey
Hallé, 2014 – Canada[44]	Understand significant others' experience of aphasia rehabilitation	12 Caregivers	Age: 58 (43–70) Gender: F=9 Relationship: Spouse=7, parents=2, other=3	Setting: Home/ Community Time point: 3–36m post-stroke	GT	Interviews
Hare, 2006 – UK[45]	Long-term support needs of patients with prevalent stroke, and their carers	6 Caregivers 27 SSs Total=33	Age: NR Gender: F=6 Relationship: NR	Setting: Rehabilitation, Home/ Community Time point: 6w-22y post-stroke	NR	FG
Hinojosa, 2007 – USA and Puerto Rico[76]	Information sources and needs of stroke caregivers	120 Caregivers	Age:62 Gender: F=111 Relationship: Spouse/ Partner=88, children=8, parents=5, other=19	Setting: Home/ Community Time point: NR	t-tests and chi-square tests	Survey
Hinojosa, 2009 – USA and Puerto Rico[79]	Association between health education needs and physical injury sustained as a result of activities related to the caregiving role	276 Caregivers	Age: Mean 66 (18–88) Gender: F=251 Relationship: NR	Setting: Home/ Community Time point: NR	Descriptive, chi-square	Telephone survey
Howe, 2012 – Australia[46]	Rehabilitation goals that family members of individuals with aphasia have for themselves	48 Caregivers	Age: 61 (24–83) Gender: F=36 Relationship: Partner=28, children=7, parents=2, other=11	Setting: Home/ Community Time point: 1–195m post-stroke	CP, CA	Semi-structured interviews
Jullamate, 2007 – Thailand[47]	Identify the reasons for the provision of informal rehabilitation services at home to stroke relatives by Thai caregivers.	20 Caregivers	Age: 53 (28–79) Gender: F=15 Relationship: Spouse=9, children=8, other=3	Setting: Home/ Community Time point: post-discharge from hospital	CA	Semi-structured interviews
Kim, 2007 – South Korea [80]	needs of family members across rehabilitation	123 Caregivers	Age: <20 – 70 Gender: F=75	Setting: Hospital, Rehabilitation	t-test, one-way ANOVA	Surveys – in person and mail

Author	Purpose	Sample size	Caregiver characteristics	Setting and time point	Methodology	Data Collection
	treatment phases and treatment settings		Relationship: Spouse=66, children =42, sibling=3, parent=6, other=6	Time point: NR		
Kniepman, 2014 – USA[84]	Impact caregivers' activities, and identify differences as per race/ethnicity through the lens of occupation	12 Caregivers	Age: 62 (37–73) Gender: F=10 Relationship: Spouse = 12	Setting: Home/ Community Time point: at least 6m post-stroke	Quantitative: non-parametric Qualitative: Inductive CA	Quantitative: questionnaires Qualitative: Semi-structured interviews
Kong,2011 – Hong Kong[73]	Investigate provision of speech-language pathology services and community resources for persons with aphasia and their families, family members' perception of the service quality	37 Caregivers	Age: NR Gender: NR Relationship: Spouse=30, Children=7	Setting: Home/ Community Time point: 4–71m post-discharge from hospital	Descriptive	Self-administered questionnaire
Lawrence, 2010 – UK[48]	Explore the beliefs and perceptions of patients and family members regarding the provision of lifestyle information following stroke	20 Caregivers 29 SSs 7 PWA Total=49	Age: Median 64 (42–79) Gender: F=9 Relationship: Family members	Setting: Home/ Community Time point:>6m post-stroke	FW	Focus groups using semi-structured topic guide
Lawrence, 2013 – UK[49]	Explore the experience of stroke from the perspective of family members of young adults with stroke	12 Caregivers	Age: 17–71 Gender: F=9 Relationship: Spouse=4, children =4, parents=3, other = 1	Setting: Home/ Community Time point: 3m-2y post-stroke	Phenomenology Merleau-Ponty's	Unstructured face-to-face interviews
Lee, 2011 – Hong Kong[50]	Explore the coping strategies of Chinese family caregivers of stroke-impaired older relatives	15 Caregivers	Age: 25–80+ Gender: F=10 Relationship: Spouse=12, children=3	Setting: Home/ Community Time point: NR	GT	Interviews
Lin, 2010 – USA[51]	Needs of family caregivers in the Chinese-American community and to develop training videos for caregivers on dressing stroke survivors	40 Caregivers	Age: 51–87 Gender: F=35 Relationship: Spouse=24, Parent=12, Friend=4	Setting: Home/ Community Time point: 1m post-discharge	NR	Semi-structured interviews
Lutz,2007 – USA[52]	Identify postdischarge needs of veterans with stroke and their caregivers and design care coordination/home-telehealth program to address these needs	10 Caregivers 12 SSs Total=22	Age: 70 (57–86) Gender: F=10 Relationship: Spouse/ Partner n=10	Setting: Home/ community Time point: 3m-5y post-stroke	GT with dimensional analysis	Open-ended, unstructured interviews

Author	Purpose	Sample size	Caregiver characteristics	Setting and time point	Methodology	Data Collection
Lutz, 2011 – USA[4]	Explore the needs of stroke patients and their family caregivers as they transitioned through the stroke care continuum from acute care to inpatient rehabilitation to home	19 Caregivers 19 SSs Total=38	Age: 58 (23–82) Gender: NR Relationship: Spouse=14, Children=4, Parent=1	Setting: Home/ Community, Rehabilitation Time point: at rehab, 4d-6w post-discharge, within 6m post-discharge	GT – dimensional, comparative analysis	Loosely structured interviews
Lynch, 2008 – USA[53]	Perspectives on post-stroke QoL	6 Caregivers 9 SSs Total=15	Age: 57 Gender: F=5 Relationship: Spouses=4, Parent=1	Setting: Home/ Community Time point: 2–29y post-stroke	NR	FG
MacIsaac, 2011 – Canada[82]	Explore the use of the Supportive Care Needs Framework as an overall guide to identify the wide spectrum of needs of the family caregivers of patients with stroke	10 Caregivers	Age: 55.7 (40–72) Gender: F=10 Relationship: Spouse=5, children=5	Setting: Hospital Time point: NR	Quantitative: Descriptive Qualitative: NR	Survey and focus groups
Mackenzie, 2007 – UK[78]	Support required by family carers for stroke survivors	42 Caregivers	Age: 62 (28–84) Gender: F=29 Relationship: Spouse/ Partner =29, children=10, parents=2, other=1	Setting: Hospital, Home/ Community Time point: 1w before discharge and 4–6w post-discharge	Descriptive	Survey
Mackenzie, 2013 – UK[83]	Feedback of participants in the Living with Dysarthria programme, to inform its perceived usefulness and guide future development	4 Caregivers 9 PWD Total=13	Age: NR Gender: F=4 Relationship: Spouse=3, other=1	Setting: Hospital Time point: 3–72m post-stroke	Quantitative: Descriptive Qualitative: TA	Written questionnaire and focus group
Mak, 2007 – Hong Kong[77]	Changing needs of Chinese family caregivers before and after stroke survivors' discharge from hospital	40 Caregivers	Age: 49 (28 – 70) Gender: F=30 Relationship: Spouse=16, children=21, other=3	Setting: Hospital, Home/ Community Time point: 2w before discharge and 2w post-discharge from hospital	Descriptive, Pearson's correlation	Scale

Author	**Purpose**	**Sample size**	**Caregiver characteristics**	**Setting and time point**	**Methodology**	**Data Collection**
McCarthy, 2015 – USA[85]	Perspectives on survivor cognitive and physical functioning and incongruence between partners' perceptions affecting spouse depressive symptoms and overall mental health	35 Caregivers 35 SSs Total=70	Age: Mean 58 (22–86) Gender: F=20 Relationship: Spouse=35	Setting: Home/ community Time point: 1–36m post-stroke	Quantitative: paired t-tests Qualitative: interpretive	Structured interview, survey
Morris, 2014 – UK[54]	Survivors', carers' and physiotherapists' beliefs about physical activity (PA) to identify how these support or hinder PA participation	12 Caregivers 38 SSs 15 Clinicians Total=75	Age: 41–80+ Gender: F=6 Relationship: Spouse=12	Setting: Home/ Community Time point: 6m post rehab	FA	FG
Obe-om, 2006 – Thailand[55]	Experiences of families with long-term stroke survivors, and families to manage care of the patients and their families	32 Caregivers	Age: 19–83 Gender: NR Relationship: Children=13	Setting: Home/ Community Time point: >1y post-stroke	Ethnography	Participant observation and interview
O'Connell, 2003 – Australia[57]	Caregivers' perspectives of their support and educational needs	28 Caregivers	Age: 55(23–74) Gender: F=16 Relationship: Spouse=18	Setting: Hospital, Home/ Community Time point: NR	NR	Face-to-face or telephone interviews
O'Connell, 2004 – Australia[56]	Perspectives on the support and educational needs they require and the coping strategies	37 Caregivers	Age:56 (23–86) Gender: F=23 Relationship: Partner=21, children=13, other=3	Setting: Hospital, Rehabilitation, Home/ Community Time point: NR	NR	Semi-structured interviews
Payne, 2010 – UK[58]	Patients' and family members' experiences of acute stroke and their preferences for end-of-life care	25 Caregivers 28 SSs Total=53	Age: NR Gender: NR Relationship: Spouse=45%	Setting: Hospital Time point: Hospital stay 1–49 d	NR	Semi-structured interviews
Perry,2011 – Australia[74]	Advance understanding of stroke caregiving using assessment methods and tools previously used	32 Caregivers	Age: 59 Gender: F=18 Relationship: Spouse=24, Children=7, Parent=1	Setting: Home/ Community Time after stroke: NR	Descriptive	Survey via telephonic interviews
Pierce, 2012 – USA[69]	Perceived dimensions of emotional strain expressed by	73 Caregivers	Age: 55 Gender: F=55 Relationship: Partner=50, children=14, other=9	Setting: Home/ Community Time point: NR	CA	Email, telephonic interviews

Author	Purpose	Sample size	Caregiver characteristics	Setting and time point	Methodology	Data Collection
	new family caregivers of persons with stroke in the first year of caring					
Ringsberg, 2003 – Sweden[59]	Stroke patients' and their relatives' conceptions of home rehabilitation, participation in the decision about home rehabilitation, participation in rehabilitation and experiences with rehabilitation team	13 Caregivers 15 SSs Total=28	Age: 67 Gender: F=10 Relationship: NR	Setting: Home/ Community Time point: 1y post-discharge from stroke unit	Phenomenography	FG semi-structured interviews
Rochette, 2014 – Canada[60]	Ethical issues regarding the systematic inclusion of relatives as clients in the post-stroke rehabilitation process	25 Caregivers 16 SSs Total=41	Age: 53 (31–72) Gender: F=21 Relationship: Spouse=8, children=10, parents=1, other=6	Setting: Hospital, Rehabilitation Time point: 4–6 w post-discharge	Phenomenology	Semi-structured interviews and FG
Rosenberg, 2009 – Thailand[61]	Informal rehabilitation caregiving provided to elderly stroke survivors	20 Caregivers	Age: 74 Gender: F=15 Relationship: NR	Setting: Home/ Community Time point: post-discharged from hospital	CA	Semi-structured interviews
Rudman, 2006 – NR[62]	Occupational experiences of stroke survivors who use wheelchairs and their primary caregivers	15 Caregivers 16 SSs Total=31	Age:68 (44–84) Gender: F=13 Relationship: Relative, formal care=2	Setting: Home/ Community Time point: wheelchair use for at least 1y	GT	Semi-structured interview
Saban,2012 – USA[63]	Experience of female caregivers who care for an adult family member who has experienced a stroke	46 Caregivers	Age: 56 (18–73) Gender: F=46 Relationship: Partner =24, children=18, parent=2, other=2	Setting: Home/ Community Time point: 3–12m post-stroke	CA	Open ended interviews
Sangvatanakul, 2010 – Australia[75]	Engage consumers in research priority-setting using a quantitative approach and to determine consumer views on stroke research priorities for clinical practice	6 Caregivers 12 SSs Total=18	Age: NR Gender: NR Relationship: NR	Setting: Home/ Community Time point: NR	Descriptive	Survey
Smith, 2008 – Canada[64]	Family caregivers' experiences and support needs during the	9 Caregivers	Age: 57 (37–77) Gender: F= 6	Setting: Rehabilitation	CA	Semi-structured interviews

Author	Purpose	Sample size	Caregiver characteristics	Setting and time point	Methodology	Data Collection
	rehabilitation phase to inform program development		Relationship: Spouse=6, children=2, other=1	Time point: NR		
Tellier, 2011 – Canada[65]	Explore the QoL of spouses after a mild stroke	8 Caregivers	Age: Mean 57 (45–69) Gender: F=6 Relationship: Spouses=8	Setting: NR Time point: 3m post-acute care discharge	CP	Open-ended interviews
Van Dongen, 2014 – Austria[66]	Working carers' occupational experiences and strategies during a period of pronounced life changes	3 Caregivers	Age: Mean 56 (49–59) Gender: F=3 Relationship: Wife=2, daughter=1	Setting: Home/ Community Time point: NR	Interpretative Phenomenology	Semi-structured interview
Vincent, 2007 – Canada[67]	Met and unmet rehabilitation needs of older adults who had suffered a stroke	12 Caregivers 17 SSs 25 HCPs 18 HCMs Total=72	Age: 41–69 Gender: F=9 Relationship: Spouse=10, daughter=2	Setting: Home/ Community Time point: < 1 – 9+ y post-stroke	NR	FG, individual interviews
Winkler, 2014 – USA and UK[68]	Explore how carers of PWA perceive their roles and responsibilities; examine consequences of carrying out carer roles and duties, in terms of both the carer's own well-being and their relationship with PWA; investigate facilitative factors in their adaptation to the carer role	10 Caregivers	Age: NR Gender: F=9 Relationship: Spouse=6, children=3, parents=1	Setting: NR Time point: 7y post-stroke	FW	Blogs

Age is reported in years as mean and range unless noted otherwise, SS: Stroke survivors, HCP: health care professionals, PWA: Persons with aphasia, PWD: Persons with dysarthria, HCM: health care managers, GT: grounded theory, FW: framework, CA: content analysis, TA: thematic analysis, CP: Constructivist paradigm, FG: focus groups, y:years, m:months, w:weeks, NR: not reported

Table 2

Body functional needs identified from the synthesis of 66 articles (n=41, 62%)

n=26 (39%) 4 Hospital 2 Rehabilitation 23 Community 2 Not Reported	**Psychosocial function** – • mood[7, 9, 28, 36, 38, 40, 69, 74, 77, 78] – "*I'm just at the end of my tether with these mood swings. One minute he is okay, joking and carrying on and then the next he just shouts at you all the time.'*[28] • anger and agitation[30, 59, 65, 69], anxiety,[47, 81] and changes in behavior[23, 40, 70] – *"He is more irritable because he realizes his limitations.'*[65] • depression[28, 30, 31, 47, 51, 69, 81] – "*His depression … I just don't know what to do to stop it.'*[81] • motivation[7, 26, 35, 40, 43, 44, 47, 54, 55, 68] – "*Try and empower them as much as you possibly can to do the things they normally do.*"[26]
n=15 (23%) 2 Hospital 1 Rehabilitation 13 Community 2 Not Reported	**Physical function** • concern for physical function[4, 9, 30, 39, 52, 65] – *"So my biggest problem it's that worry… is he breathing?"*[89] • limb function[81] – *"Had problems using the arm or hand that was most affected …'*[81] • pain[7, 38, 40] and fatigue management,[52, 65, 75] – *"pain was a particular concern at this time.'*[88] • vision and hearing[81, 84] – "*…he doesn't see well.'*[84] • voice functions – aphasia,[68, 77] dysphasia,[77] recovery of speech[38, 70] – *"Today has been a real pushing rocks with feathers day due to this damn aphasia.'*[68]
n=10 (15%) 2 Hospital 1 Rehabilitation 9 Community	**Cognitive function**[24, 40, 77]– • comprehension,[26, 33, 81] memory,[36, 49, 81] concentration,[81] orientation,[71, 77] mental stimulation,[26] insight[85] – *"Had difficulty understanding what had been said to him/her in conversations.'*[81]
n=9 (14%) 3 Hospital 3 Rehabilitation 8 Community	**Uncertainty related to functional impairments**[9, 32, 35, 42, 56, 58, 63, 70, 74] – *"I don't know what to expect after the first day or two whether he will change or be the way he is right now...'*[42]

Table 3

Activity and Participatory needs identified from the synthesis of 66 articles (n=43, 65%)

n= 26 (39%) 3 Hospital 3 Rehabilitation 22 Community 2 Not Reported	**Healthy lifestyle** – • leisure,[26, 40, 62] and social activities[9, 25, 26, 30, 40, 54–56, 61, 68] – *Dad loves sunshine … we take him for strolls in the courtyard.'*[68] • nutrition[7, 47, 48, 50, 55, 61, 77] – *"I always prepare her a low-fat and -salt diet.'*[50] • health,[47, 50, 65, 77] spiritual health, [47] plenty of rest[41] – *"I pay more attention to her health now.'*[65] • preventing reoccurrence of disease[9, 39, 47, 49, 54, 59, 63–65, 69, 71, 72, 77] – *"But there's that worry all the time that it can come back again.'*[59]
n=15 (23%) 2 Hospital 1 Rehabilitation 20 Community	**Physical activities** – • self-care,[7, 78] grooming,[81] cooking,[35, 81] bathing,[81] feeding,[40, 77, 81] dressing,[35, 40, 81] and bathroom and toileting [25, 35, 40, 52, 59, 77, 78, 81] – *"Well she can't control her bladder.'*[25] • mobility[9, 25, 37, 62] – *"I'm trying to keep his mobility as much as I can…'*[62] • transfers[27, 40, 52, 53, 62, 81] – *"had problems getting up and down out of a chair.'*[52] • walking[37, 40, 54]– *"So then the next thing was to start to get him mobile, to go for a walk.'*[87] • balance and posture,[37] physical activity,[54] stair climbing[81]
n=15 (23%) 1 Hospital 1 Rehabilitation 13 Community 1 Not Reported	**Independence** – • normalcy and return to pre-stroke activities[4, 26, 36, 43, 49, 50, 53, 62, 66, 68, 69] – *"... I would do anything to get her back.'*[86] • work[26, 35, 49, 53, 75] – *"(he's) depressed because he's not working.'*[53] • ability to drive[4, 26, 33, 49, 75] – *When they lose their license…that is the most demeaning thing.'*[26] • stroke survivors' autonomy[70] – *"So he talks to me and asks me to call. I then repeat it, as if it was him talking, not me."* [70]
n=11 (17%) 2 Hospital 1 Rehabilitation 9 Community 1 Not Reported	**Speech and ability to talk** – • conversations and social communication,[26, 36, 44, 46, 68, 76, 78] expression,[44, 68, 81] speaking[33, 39, 44, 68, 70] – *"she can't talk, and that … hurts the most.'*[83]
n=2 (3%) 2 Community	**Cognitive activities –** decision making,[49] judgment[40]– *"you end up having to make all the decisions, and, Och! It is wearing! I mean I love him, I love him dearly but just occasionally you think, Just decide'*[49]
n=2 (3%) 1 Hospital 1 Rehabilitation 2 Community	**Uncertainty related to limitations in activities and participation** [41, 49] **– "***Everything gets a little bit more complicated and new even going to see friends or people who want to come up to see her'*[41]

Table 4

Environmental needs identified from the synthesis of 66 articles (n=61, 92%)

n=50 (76%) 14 Hospital 12 Rehabilitation 40 Community 2 Not Reported	**Support** – • communication with health care professionals[4, 24, 26–28, 30–32, 34, 36–38, 41, 44–46, 48–50, 52, 57–60, 63, 64, 67, 73–75, 82, 83] – *"It would have been nice to have somebody sit down with me and say this is what's happened."*[81] • family and friends[4, 9, 26, 28, 37, 40–42, 44, 49, 51, 52, 55–57, 61, 63, 64, 66, 68, 69, 71, 73, 74, 78, 80, 82] – *"..She can't really be lonely with the contacts she has with her family."*[26] • finances[4, 24, 28, 30, 35, 36, 40, 46, 51, 55, 56, 61, 63, 65, 73, 74, 77, 78, 84] – *"It was a big change in the family! He (stroke survivor) used to be the source of family income and after the stroke, we had no income."*[80] • support groups[26, 35, 57, 83] –"Since I go to these support groups, I can see what he does and what all other ones do."[35]
n= 44 (67%) 12 Hospital 10 Rehabilitation 34 Community 2 Not Reported	**Services –** • *Rehabilitation services* [4, 24, 26, 29, 30, 37, 49, 59] – *"…you know, it's been over a week now, and I feel it's really bad that he's had nothing, professionally."*[87] – additional rehabilitation, [26, 28, 29, 46, 57, 59, 68, 73, 83] family centered approach[60, 77]– *"family-centered approach as ideal."*[77] – preferred setting – inpatient rehabilitation,[4] long term care,[73] in-hospital rehabilitation,[59] community based interventions,[57, 83] day care centers,[73] outpatient[73] and home.[28, 32, 55, 59] – transitioning home[4, 43, 65, 75] – *"it wasn't done at the hospital like you would at home you know."*[43] – speech therapy[26, 44, 73] – *"get themselves to a speech pathologist on a regular basis."*[26] – group therapy[83] and intensive[77] – *"My husband requires more intense rehabilitation."*[77] • information – diet and nutrition,[48] discharge to community,[4, 27, 34, 37, 39, 48, 73] support services and other resources,[31, 45, 57, 67, 73–75, 78, 80, 82] accommodation and accessibility,[4, 45, 48] rehabilitation,[46, 73, 75] transfers,[27, 76, 79] self-care,[79] financial resources,[32, 63, 76, 79, 80] respite,[80] medications,[38, 58, 76, 77, 79] abuse prevention,[79] aphasia,[44, 46, 73] psychosocial condition,[57, 76, 79, 80] treatment of residual effects,[28, 31, 37, 38, 45, 57, 61, 73, 74, 76, 78–80, 82, 83] urinary incontinence,[25] and safety.[76, 79] • other services [27, 30, 32, 36, 37, 45, 54, 57, 65, 75] – gymnasium,[54] meals,[30] follow-up care,[75] paid caregivers[26, 30, 41, 46, 51,74]
n=17 (26%) 1 Hospital 2 Rehabilitation 16 Community	**Safety** – • falls[4, 7, 9, 30, 39–41, 49, 52, 62, 71, 85] –*"I felt anxious and worried that she may get up by herself and fall."*[80] • leaving stroke survivor alone[9, 26, 39, 41, 52, 65, 69, 74, 85] – "*…is [she] capable of living on her own."*[26] • medication administration,[4, 39, 44] – *"I'm just terrified that I'll give him the wrong pill at the wrong time."*[4]
n=14 (21%) 2 Hospital 1 Rehabilitation 13 Community 1 Not Reported	**Accessibility and Accommodation** – • toilet, [25, 62] public places, travel and transportation [30, 62, 65, 67, 81] – *"We waited for an hour for a bus with a wheelchair platform."*[80] • assistive technology [39, 74, 78] – wheelchair,[41] walkers,[59] augmentative communication[33] – *".. negotiate with the staff about not discharging their partners before the assistive devices were prescribed and installed"*[89] • *home and vehicle* [55, 59, 61, 67] – *"We used non-slippery tiles as the bathrooms floor and widened the door so that we could take her in to take a bath in a wheelchair."*[55]

n=11 (17%) 2 Hospital 9 Community 1 Not Reported	**Uncertainty related to environmental factors** [9, 30, 34, 42, 50, 52, 57, 63, 65, 71, 84] **–** **“** *everything was very difficult when we first got him home’*[52]