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A systematic review of the impact of stroke on social support and social networks: associated factors and patterns of change

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Running head: social support after a stroke

Key words: stroke; systematic review; social support; social network; social isolation

Abstract

Objective: Identify what factors are associated with functional social support and social network post stroke; explore stroke survivors' perspectives on what changes occur and how they are perceived.

Data sources: The following electronic databases were systematically searched up to May 2015: Academic Search Complete; CINAHL Plus; E-journals; Health Policy Reference Centre; MEDLINE; PsycARTICLES; PsycINFO; and SocINDEX.

Review methods: PRISMA guidelines were followed in the conduct and reporting of this review. All included studies were critically appraised using the Critical Appraisal Skills Program tools. Meta-ethnographic techniques were used to integrate findings from the qualitative studies. Given the heterogeneous nature of the quantitative studies, data synthesis was narrative.

Results: 70 research reports met the eligibility criteria: 22 qualitative and 48 quantitative reporting on 4,816 stroke survivors. The qualitative studies described a contraction of the social network, with non-kin contact being vulnerable. Although family were more robust network members, significant strain was observed within the family unit. In the quantitative studies, poor functional social support was associated with depression (13/14 studies), reduced quality of life (6/6 studies) and worse physical recovery (2/2 studies). Reduced social network was associated with depression (7/8 studies), severity of disability (2/2 studies) and aphasia (2/2 studies). Although most indicators of social network reduced post stroke (for example, contact with friends, 5/5 studies), the perception of feeling supported remained relatively stable (4/4 studies).

Conclusion: Following a stroke non-kin contact is vulnerable, strain is observed within the family unit, and poor social support is associated with depressive symptoms.

A systematic review of the impact of stroke on social support and social networks: associated factors and patterns of change

The social impact of having a stroke is considerable. Stroke survivors take part in fewer social activities¹, family life is disrupted², and contact with friends and the wider network is vulnerable³. Social isolation is a commonly reported sequela, and may disproportionately affect those with aphasia (language difficulties)⁴. The two most relevant systematic reviews in the stroke literature have focused on specific aspects of social support post stroke: the association with health-related quality of life⁵ and the impact on working age adults⁶. A comprehensive review that explored all factors associated with social support post stroke including recovery and depression, and which analysed how changes to social support were perceived by the stroke survivor, may enable stroke services to be more sensitively designed.

For the purposes of this review social support has been conceptualised in terms of function and structure. Functional support refers to the provision of supportive functions by other persons⁷. These functions may include emotional support; tangible, or practical, support; informational support, such as guidance or advice; and social companionship, for example, in leisure or recreational activities⁸. A further distinction may be made between *received* versus *perceived* functional support. While received support (observed acts of support) may vary according to life circumstances, perceived support, or the subjective experience of feeling oneself to be supported, is understood to remain relatively stable⁹. In a meta-analysis of 23 studies the association between perceived and received support was found to be only moderate ($r = .35$)¹⁰.

A related concept to functional support is the structure through which support may be provided, or the 'social network'. Aspects of social network structure may include: size of network; and composition of network (for example, whether network members are family, friends, neighbours). Characteristics of individual network ties may include: frequency of contact; reciprocity; duration. Many social network indices also include frequency of participation in community or religious organisations, or some other indication of community integration⁸. While a well-functioning and diverse social network is likely to facilitate receipt of functional support, it may be possible to receive adequate functional support from only one or two network members⁷. Further, a social network confers benefits other than functional support: Cohen and Wills⁷ argue that feeling integrated and embedded in one's social network 'provide(s) positive experiences... positive affect, and sense of predictability and stability in one's life situation, and a recognition of self-worth.'

The purpose of this review was to describe what happens to functional social support and social networks following a stroke, and identify what factors have been associated with or predictive of social support and social networks. A subsidiary aim was to explore the impact of aphasia on maintaining social contacts. The quality of the included studies was reviewed in order to establish the strength of the existing evidence. Of particular interest were stroke survivors' perceptions as to how and why social changes were occurring, what impact these changes were having on their lives, and what support they most valued. For this reason, qualitative evidence which explored the 'lived experience' of having a stroke has been systematically included in this review, and considered alongside quantitative evidence.

Methods

The PRISMA guidelines formed the basis of the conduct and reporting of this systematic review¹¹.

Eligibility criteria. Studies were considered eligible if they were research reports that explored functional support or aspects of the social network following a stroke. Only English language, peer reviewed publications were included. There was no restriction on publication date, geographical location, sample size or duration of follow up. Participants had to be adults who had had a stroke. Studies were excluded if participants were caregivers rather than stroke survivors; or if they reported on mixed populations unless stroke results were reported separately. The review did not include studies where the only social network indicator was either marital status or living arrangements: single indicators such as these have been found to be less predictive of outcome than more complex measures¹².

For quantitative studies, an additional criterion was that only studies using validated measures of functional support were included: when assessing subjective feelings, well-constructed psychometrically sound instruments give more reliable results¹³. It was considered that aspects of social network could be more reliably assessed without using a validated scale as they are potentially less subjective.

For qualitative studies, an additional criterion was that they should use an established method of analysing the data. Further, only qualitative studies that reported on an aspect of social support or network as a main finding were included.

Sources of information and search strategy. The following electronic databases were searched: Academic Search Complete; CINAHL Plus; E-journals; Health Policy Reference Centre; MEDLINE; PsycARTICLES; PsycINFO; and SocINDEX. These databases were searched for peer-reviewed journal articles with the following search strategy (see also Appendix A):

- Field: Title. Search terms: ‘stroke’ OR ‘aphasia’
- AND Field: Abstract. Search terms: ‘social support’ OR ‘social network’ OR ‘social activity’ OR ‘social satisfaction’ OR ‘lonel*’ OR ‘social participation’

The initial search was conducted by the first author (SN) in July 2013, and then re-run in May 2015. Search results were stored on EBSCOhost. Further studies were considered from following up references, or through recommendation by expert advisors.

Screening, data extraction and critical appraisal. The abstracts of all journal articles that came out of the above search strategy were screened against the eligibility criteria. Where it was not possible to assess the eligibility based on the abstract alone, the full text was reviewed. Data extraction and critical appraisal was undertaken by the first author (SN) for all studies. For a randomly selected third of the papers critical appraisal was undertaken independently by a second reviewer (BM, KH, or KH). Any discrepancies were resolved by discussion within the team. Reviewers were not also authors of papers they appraised.

For each eligible study the following information was extracted: publication details; study aims; country and setting; timing of assessment(s); study population (including presence/severity of aphasia, severity of stroke, major exclusion criteria); measures used; main results.

Qualitative studies were critically appraised using the Critical Appraisal Skills Program (CASP) tool for Qualitative Research¹⁴. Quantitative studies were assessed using the Critical Appraisal Skills Programme (CASP) tool for cohort studies¹⁵. These tools assess the rigour, validity and value of the included studies. In order to make the cohort appraisal measure more sensitive to the stroke population, items from the critical appraisal tool developed by Counsell and Dennis (2001)¹⁶ on internal and external validity were incorporated into it. Studies that did not meet standards for quality were not included in the data synthesis.

Data analysis: qualitative. Meta-ethnography was used to synthesise findings. This involves the interpretive integration of findings from qualitative studies¹⁷. Initially, findings that related to social support were summarised, using the terms and concepts found in the studies. Concepts were grouped to construct descriptive themes, a thematic framework evolving through this process. In the present study, two authors (SN and BM) independently noted the themes that emerged from the 22 papers to ensure that all relevant thematic material was included in the final framework, and that the written synthesis preserved the integrity of the original sources.

Data analysis: quantitative. The quantitative studies included in this review were not homogenous in study design, measures used, study aims, or participant characteristics. This made it inappropriate to conduct statistical meta-analysis¹⁸. Instead, a narrative synthesis of the evidence is presented.

Results

Study selection. Electronic database searches resulted in 493 references. A flow diagram (Figure One) shows the reasons for exclusion at each stage. The review includes 70 reports: 22 qualitative and 48 quantitative.

[Figure One about here]

Qualitative studies

The 22 qualitative reports are based on 20 studies. Brief study details are provided in Table One. Ten studies reported on the general stroke population (n = 283); eight exclusively on people with aphasia (n = 175); one reported on people with dysarthria (n = 24); and one on right hemisphere stroke (n = 12). Detailed results of the critical appraisal of included papers are presented on-line in Appendix B. Qualitative methodology was appropriate in all cases and the research design was justified.

[Table One about here]

Qualitative meta-ethnographic synthesis

This synthesis examines the impact of having a stroke on a person's relationships with their family, friends and social acquaintances. A summary of the synthesis is provided in Figure Two.

[Figure Two about here]

Family

As one participant wrote, a stroke 'is actually a family illness' (p29)¹⁹, and the impact of the stroke on family relationships was described in 19 of the 22 reports.

Disruption to family relations

The stroke was described as the cause of stress and disharmony within the family^{4, 19-28} and at the very least caused a 'rearrangement' (p123) of a family's patterns of giving and receiving²⁹. The reasons for the disruption are explored below.

Lost roles/ change in roles: The stroke caused people to be unable to fulfil previously valued roles. These included the roles of provider and worker, protector or carer. The stroke both challenged their ability to take on the parental and grandparental role^{20-22, 25-28}, and also made it harder to support aging parents, and fulfil the role of son or daughter²².

Shifting roles within a marriage were also a cause of friction, marital strain, and reduced reciprocity^{19, 21-23, 26-28}. Some partners were perceived as unable to cope²³ or understand^{19, 21}; and became over protective or took over e.g. with decisions^{22, 30, 31 27, 32}. Intimacy and sex life were also disrupted^{22, 26, 28, 31}.

A recurring theme was the difficulty associated with the loss of 'giving' roles, and instead be forced into the position of 'receiving'. Such role changes were reported to be associated with helplessness and frustration²⁴, disruption to self-identity^{24, 26}, distress at feeling dependent²²⁻²⁸, and guilt^{20, 24}.

Changes to the daily routine/ lost activities: For many, post stroke the 'fabric of everyday life' (p47)²² changed, and instead of being focused around work or other out-of-house

activities, it was more home-based, consisting of washing, feeding, lifting and managing other activities of daily living^{4, 22, 24-27, 29 32}. Spending large amounts of time at home together was a cause of tension^{4, 22, 28}. Stroke survivors with young children described restrictions in their ability to participate in family activities, for example, taking their children swimming or reading a bed-time story²⁷.

Dealing with strong emotions: A range of strong emotions were described post stroke, for example, anger, depression, frustration. These could be difficult for the family members to deal with²². Fears of being rejected by family members, or not wanting to ‘worry’ their family, also meant a subset forced themselves to be cheerful or not open up about their difficulties.²⁸

Communication Disabilities: Difficulty communicating also disrupted family relationships, and was a further cause of stress^{4, 20, 22, 33}.

Factors which made family life more harmonious

A number of studies explored what factors enabled people to find successful ways of living within their family post stroke^{4, 19, 22, 29, 31, 33}. The main themes to emerge were:

Being able to contribute/ maintain roles: Caring for others, resuming daily routines, maintaining relationship roles where possible, and finding ways to contribute to family life, reciprocate, and engage in mutual help and support, were all seen as protective, making the person feel valued and competent^{29, 31, 33, 34}.

Negotiating support and independence: Those who were able to communicate their need both for assistance and independence throughout their recovery perceived themselves to be

more connected³¹. Couples, in particular, needed to find the ‘delicate balance’(p48)²² between providing needed tangible support, while at the same time fostering the stroke survivor’s independence and sense of competence^{19, 22, 29, 31, 34}.

Being able to express and receive intimacy, love and support: Being able to express love, whether to a partner or other family member, was also associated with successful coping^{22, 23, 31}, as was feeling valued and supported^{19, 22-25, 29, 35}.

Friends, acquaintances and social participation

What happens to friends, acquaintances and social activities?

A consistent theme across studies was that stroke survivors had difficulty maintaining contact with their pre-stroke friends^{3, 4, 21, 22, 30, 36, 26, 27}, participated in fewer community and social activities^{3, 20, 23-26, 31}, and engaged in fewer interactions with acquaintances and strangers^{3, 20, 36}. Many participants felt isolated and lonely^{4, 20, 25, 30}, and a subset of participants lacked the physical presence of anyone else for most of the time^{4, 30, 31}.

While friends might initially rally around, contact then typically dropped off^{22, 27, 37}. Stroke survivors were also more likely to receive visits than to make visits^{24, 36}, and were less likely to initiate plans than age-matched controls³⁶.

Perceived causes of reduced social participation

Physical and cognitive disability: New physical difficulties such as pain, reduced mobility, loss of balance, or fear of falling made social participation more difficult^{3, 4, 24, 26, 27, 30, 32}. Even apparently mild disabilities impacted on participation e.g. not being able to answer the phone

quickly³², or feeling self-conscious using cutlery in a restaurant²⁷. Disability also meant many needed to plan for social engagements carefully rather than be spontaneous^{26, 27}. Increased dependency made it harder to see friends independently^{25, 37}, and those who were housebound were only able to see friends who were physically well enough to visit them³. Difficulties with memory³⁰ and ‘thinking’²⁴, were also cited as reasons for reduced participation.

Fatigue: Feeling exhausted impacted on participants’ desire and capacity to socialise, both in and out of the house^{3, 20, 21, 26, 27, 30}. It also made it harder for participants to initiate social contact³. The effort required for carrying out ADL meant it was challenging to find the extra energy to engage in former social activities²⁶.

Relocation/ institutionalised living: A subset of participants relocated as a consequence of the stroke^{4, 29, 34, 35}, yet moving house made it harder to keep in touch with formerly local friends^{22, 24}. A further challenge to a person’s social identity was the loss of personal history that could take place on entering an institution such as a nursing home⁴.

Environmental barriers including lack of access and driving cessation: Not having a driving licence made it harder to participate^{23, 25, 34}, particularly if there was no family member available to give lifts³¹. Lack of transport^{24, 31, 35}, difficulty accessing transport^{3, 30 27}, or an unwillingness to impose on others for lifts²⁵ were also cited as barriers to participation. Other environmental factors, such as anxiety about negotiating steps, lack of suitable seating or toilets, and background noise constituted further barriers^{3, 27}.

Situation specific: When a person gave up an activity they tended to lose contact with the friends and social contacts associated with that activity. Activities described included: work³,

4, 20, 22, 24-28, 30, 34, 37; educational courses²⁸, sport, attending religious services, cultural activities and a variety of other social or semi-social activities^{3, 4, 24}.

Financial: The stroke often meant a sudden end to employment, which in turn could lead to financial pressures, making it harder to afford a round of drinks, or a semi-social activity such as golf^{4, 22, 28}.

Internal barriers: A range of emotions were cited as negative influences on whether a person participated. A subset of participants seemed to be withdrawing into themselves following the stroke and avoiding contact^{3, 4, 20, 25-28, 30}. Participants described feeling vulnerable and anxious, and felt frightened or lacked confidence to go out, especially on their own^{3, 4, 26, 30, 32}. Retreating was a strategy for coping, and protecting themselves from situations which might damage their self-esteem^{3, 26}.

Several studies found that a proportion of participants were embarrassed or ashamed about their disabilities, including aphasia and dysarthria^{3, 20-22, 24, 27, 30}, which in turn led to a reluctance to socialise or participate^{20, 22, 24, 30}. Participants did not want others to see them unwell or disabled^{3, 20}. They described feeling less good company post stroke³. Being fearful or reluctant to ask for help were also cited as barriers to participation^{26, 32}.

Communication difficulties: Communication disability had a negative impact both on participation, and on the nature and quality of social interactions. Maintaining relationships was a challenge when the participant was no longer able to have the same in-depth discussions as they had done prior to the stroke^{20, 22, 27, 33, 37}, make jokes as they used to^{3, 22, 27, 36}, or join in group conversations^{20, 21, 27, 30}. They described feeling that their contribution was diminished, that they were less able to express their opinions and thoughts, that interactions

were effortful rather than enjoyable, and they felt less included^{20, 27}. In addition, difficulties writing letters and speaking on the phone made it harder to continue a friendship^{3, 20, 27}, both reducing contact and also restricting their ability to arrange social engagements²⁰. Aphasia also meant maintaining a social media presence (e.g. blogging, Facebook) was time consuming and effortful²⁷.

The attitude of friends and members of the community: Stroke survivors described acquaintances and former friends avoiding them in everyday situations (e.g. when out shopping)^{26, 32}. They felt stigmatised, and that others had pre-conceived stereotypes which positioned them as incapable or incompetent^{27, 32}. They described situations where they were ignored or talked down to^{20, 27, 32}. Friends were perceived as finding it difficult to be with an ‘ill’ person²⁸. A subset of stroke survivors chose to disguise or hide their symptoms, and avoid disclosing that they had had a stroke^{3, 29, 32}.

Aphasia appeared to present specific challenges. Friends were described as feeling awkward, embarrassed or frightened of the aphasia^{4, 22, 30}; of being too impatient^{22, 30}; not being able to show empathy or acceptance^{22, 30, 37}; and unwelcome pity^{3, 20, 37, 27}. Other people treated them as though they were simple minded, mentally ill or deaf^{20-22, 27, 30, 37}; their speech mocked or ridiculed³.

A new selectivity/ changing social preferences

A new selectivity was observed in six studies^{3, 19, 24, 26-28}. There was a sense that people needed to make careful choices about which friends and family they invested energy in^{24, 28}, and surround themselves with individuals they perceived to be helpful¹⁹. For some, there was a new preference for seeing family and close friends^{3, 27}. Interactions with strangers and

acquaintances, especially large noisy gatherings with multiple conversations, were valued less post stroke^{3, 26-28}.

Factors which facilitated social participation

Attitude of the stroke survivor: The motivation and attitude of the stroke survivor was described as a key facilitator of social participation^{25-27, 30, 32, 34}. Those who re-engaged socially were described as being determined, showing endurance even stubbornness, and persevering despite the difficulties and the reactions of others^{26, 27, 30, 32, 34}. They were also proactive in going out and making friends³⁷, took a positive approach³⁴, and were adaptable and flexible in problem solving^{32 26}. Humour was another factor found to assist stroke survivors in re-establishing social relationships²⁵.

Support from family in re-engaging socially: some spouses facilitated social contact with old family friends, and supported the stroke survivor in engaging in new social activities^{3, 4, 30, 32}.

Factors which facilitated preserved contact with pre-stroke friends: A number of factors were identified which made a friendship more likely to be maintained following a stroke. These included: the quality of the friendship prior to the stroke^{3, 30}; living locally³; the availability of the friend, for example, a friend in reasonably good health^{3, 22}; and regular, supportive groups, for example, the British Legion, or a local church³.

The value of social relationships and support

The value of friendships and activities

Participants who regained social and community activities post stroke described the positive value of this in several studies^{23, 27, 30-34, 37}. It conferred a sense of achievement²³, confidence and enjoyment^{23, 30, 34, 37}, and that they were contributing and were valued and useful members of their community^{31, 32, 37}, as well as enabling them to feel connected to friends and family^{34, 37}. Positive friendships were seen as a source of fun, emotional support and an important component of ‘living successfully’ with aphasia^{34, 37}.

The role of new friends and stroke/aphasia groups

In terms of new friends made since the stroke, these appeared to be predominantly made through stroke or aphasia groups^{4, 37}, as well as social media²⁷.

Positive contribution of attending groups. Several studies stressed the value of meeting others ‘in the same boat’^{22, 23, 25, 33, 37}. Participants reported feeling understood^{23, 25, 37}, accepted^{25, 33}, and encouraged^{22, 23, 25, 38}. Meeting other stroke survivors could help ‘normalise’ the stroke experience^{23, 25, 34, 37}, and enable a person to construct a positive post stroke identity²². The value of mutuality was also described^{25, 34, 37}. Participants also enjoyed and had fun at groups^{23, 25, 33, 37}, as well as making new friends and social contacts^{21, 27, 36-38}.

Negative experiences of group membership. For a proportion of participants, entering a stroke group was a difficult or painful process: some did not want to identify with others who had a stroke^{4, 22, 25}; found it depressing comparing their recovery with others²², or distressing to witness those worse affected³⁴; young stroke survivors could be put off by a room full of

older people^{4, 22}. Activities at day centres and volunteer-led groups were described as inappropriate (for example, craft activities more suited to young children), and excluded those with severe aphasia (for example, pen and paper games)⁴. There were additional issues of access for those with limited transport options³⁵.

Social support, adjustment and successfully living with stroke and aphasia

Meaningful relationships were identified as key to successfully living^{19, 33, 34, 37, 38}, adjusting^{22, 23, 25, 31} and coping^{21, 23, 29} with stroke and aphasia. Figure Three describes the support functions consistently described as valuable by stroke survivors in the included studies.

[Figure Three about here]

Quantitative studies

Study characteristics of included quantitative reports: The 48 reports were based on 40 studies, 23 of which were cross-sectional. Brief details about the studies are provided in Table Two. In total, data from 4,322 stroke survivors were included in the studies.

[Table Two about here]

Risk of bias within quantitative reports. Those studies considered most unreliable were excluded from analysis. This applied to eight studies, where there were concerns that the population could be biased. Full details of the excluded studies are provided in the on-line Appendix C. The remaining 48 reports were considered sufficiently reliable to be included in the review. Full critical appraisal of included studies is provided in on-line Appendix D.

Synthesis of results: quantitative studies

A summary of results is provided in on-line Appendix E in table format.

What happens to social support and social network post stroke?

On average, stroke participants perceived themselves to be well-supported following a stroke (6/6 studies³⁹⁻⁴⁴), and this remained stable over time (4/4 studies^{40, 43-45}). Further, contact with the most immediate family, such as children (2/2 studies^{46, 47}) and close attachment figures (2/2 studies^{48, 49}) was stable. However, family functioning deteriorated following the stroke (2/2 studies^{2, 45}). Furthermore, the number of friends and contact with friends reduced or was less than controls (5/5 studies^{1, 46-48, 50}). Similarly, the size of network reduced or was less than controls (2/2 studies^{1, 50}), as did involvement in social activities (3/3 studies^{1, 47, 51}). On-line Appendix F gives more detailed results.

Relationship between social support/network and other variables

Neither overall social network nor functional support were the dependent variables in any study. Therefore, this analysis is only able to assess social support as an independent variable, associated with a variety of other variables in either univariate or multivariate analyses.

Figure Four provides an overview of the main results.

[Figure Four about here]

Depression (see also on-line Appendix G). Perceived functional social support was associated with depression/ depressive symptoms following a stroke in both the acute and chronic stages (12/12 studies^{40, 45, 52-61}). The evidence is less strong for received functional support (1⁴³/2⁶²).

For individual subscales, significant associations were found with emotional support (2⁴³, 5⁵⁵/3⁵⁷); and informational support (2/2)^{55, 57}, but not tangible support (0/3)^{43, 55, 57}.

There was also evidence that some elements of the social network were associated with depression/ depressive symptoms. These were: family functioning (1/1)⁴⁵; availability of close confiding relationships (2/2)^{48, 49}; social activities (1/1)⁶³; and contact with friends and relatives (3/3)^{48, 53, 64}. Satisfaction with social network was found to be associated with depression in 2^{40, 45}/3⁴⁸ studies. Depression was only weakly associated with overall social network (1/1)⁵²; and not associated with size of network (2/2)^{40, 65}.

In terms of predicting future depression, 5^{40, 45, 48, 56, 61}/6⁴³ studies reported that aspects of social support or network (for example, dissatisfaction with pre-morbid social network⁴⁰; perceived functional support at time of stroke⁴⁵) were significant predictors.

Health-related quality of life (HRQL) (see also on-line Appendix H). 4^{41, 42, 66, 67}/ 5³⁹ studies found perceived functional support to be associated with HRQL, the association particularly strong in those studies (2/2)^{41, 67} using measures which focused on *satisfaction* with perceived social support in the sub-acute and chronic stage. The study finding no association between overall functional support and HRQL, did subsequently report in a separate paper that two specific subscales were significantly associated: social companionship and informational support⁴⁶.

By contrast, the single study exploring *received* support⁶² did not find overall functional support to be associated with HRQL, although it did find a significant association between the tangible support subscale and HRQL.

Overall size of network was found to be significantly associated with overall HRQL for the whole stroke population⁶⁷; for women only⁴⁶; and with specific HRQL domains⁶⁸.

Physical outcomes. Overall functional support was not correlated with concurrent measures of activities of daily living (ADL) in 4^{52, 56, 62, 69/5}⁵⁸ studies; one study⁶² did find an association with tangible support. However, there is some evidence that received functional support, particularly emotional support, measured shortly after the stroke^{43, 70}, was associated with better recovery. Similarly, overall social network measured prior to the stroke was also associated with better recovery⁷¹. In addition, few social contacts may increase the likelihood of a future adverse event such as recurrent stroke or death⁷². There is also limited evidence that in the chronic phase, those with more severe disability spend less time out of the house⁷³, and engage in fewer social activities⁵¹.

Severity of Aphasia: There is limited evidence that severity of aphasia predicts time spent out of the house⁷³ and involvement in social activities⁶⁸. There was no significant association found between levels of perceived social support and presence/ severity of aphasia, however^{40, 46}.

Cognition: 2^{56, 69/3}⁵⁸ studies found no significant association between concurrent functional social support and cognition.

Other factors: perceived functional support was found to be significantly associated with community integration⁷⁴; optimism, subjective well-being, and meaning in life⁷⁵; and coping in a European sample, but not an Asian sample⁷⁶. Further, perceived support partially mediated the relationship between driving cessation and community integration⁷⁷.

Discussion

Seventy reports exploring either functional social support or social network, and reporting on 4,816 stroke survivors, were included in this systematic review. Both the qualitative and the quantitative syntheses found that contact with family remained relatively stable, albeit with increased tension and disharmony. Further, the perception of feeling supported appeared to remain stable. By contrast, contact with friends and involvement in social activities was found to reduce. The perceived causes included: physical disability, communication disability, fatigue, relocation, lack of access, internal barriers, and the stigmatising attitudes of others. Depression was significantly associated with poor functional support and also reduced social activities and few contacts with friends. The support functions perceived as valuable by stroke survivors included: emotional support (feeling valued and loved; encouragement; constancy; acceptance); receiving tangible support in a way that fostered independence; social companionship (humour, distraction); and being able to contribute/ maintain roles.

One of the strongest findings of the review was that low perceived functional support was significantly associated with depression at all stages post stroke in the quantitative synthesis (12/12 studies). This replicates the association in the general population⁷⁸. Furthermore, of the two stroke studies^{45, 64} that followed a cohort from acute to the long-term (over two years post stroke), by two years the only significant predictor in both studies were social factors. In the Astrom et al. (1993) study⁶⁴, at three years post stroke, only 7% of the depressed participants had met a friend or relative in the previous week, compared with 66% of the non-depressed participants, which is comparable to pre-morbid levels.

Kruihof et al.⁵ also reviewed the association between social support and HRQL post stroke, finding the evidence to be inconsistent: we also found that not all studies reported significant associations between overall functional support and HRQL. We would suggest that the association between *received* support and HRQL and also depression is less strong than between *perceived* support and HRQL/ depression. This pattern is also found in the general literature¹⁰. As such, perceived and received support appear to be distinct concepts, suggesting that perceived support is measuring something other than observable support transactions. It has been argued that the perception of feeling supported is based on countless ‘invisible’ and reciprocal every day support exchanges built up over many years⁷⁹; received support, by contrast, may be measuring more ‘visible’ less reciprocal support. Satisfaction with perceived support, in particular, was consistently associated with HRQL. The concept of satisfaction may more directly tap into the *way* in which functional support is being provided. The qualitative literature included in this review would suggest that the receipt of support, particularly where a person felt dependent on others, could be distressing; by contrast, feeling loved, valued and able to contribute (ie to be in reciprocal supportive relationships) was protective.

In terms of predictive models, taken as a whole, social factors such as pre-morbid dissatisfaction with social network⁴⁰, or satisfaction with perceived support two weeks post stroke⁶⁷, were predictive of later depression and poor HRQL. This would seem to support the stress buffering hypothesis⁷: those who felt connected to others at the time of the stroke appeared to have been protected from the negative psychological consequences of having a stroke. It may be that in times of acute stress a person has particular need to have supportive relationships.

A rationale for including qualitative studies was that they might be able to explain significant associations found in quantitative studies. One such association was that emotional support facilitated more complete physical recovery^{43, 70}. Tangible support was either found not to be associated with recovery, or ‘too much’ tangible support was less beneficial than moderate levels. The findings in the qualitative synthesis may help to explain this pattern. Tangible support was only found to be facilitative to recovery when it was provided in such a way as it fostered independence. Where the stroke survivor felt that their spouse/family member was taking over or being over protective, this impacted negatively on feelings of competence. Emotional support, in the form of making the stroke survivor feel valued, encouraged, and understood, was perceived as facilitating recovery.

A further finding of the review was the consistent pattern of people losing contact with friends and social activities post stroke, which was also found in a recent meta-ethnographic review of UK stroke survivors’ experiences of social participation⁸⁰. In common with this previous review, we found the causes of this to be multifaceted, and included physical disability, fatigue, and feeling withdrawn. Aphasia was also cited as a reason both for lost friends, and also changes to the dynamics of a friendship. Further, negative attitudes of friends and the community appeared to affect those with aphasia disproportionately³. The stigma described may relate to the fact that aphasia is poorly understood, or even known about, in the general population. Public awareness of aphasia is significantly lower than other neurological conditions with a similar prevalence, such as Parkinson’s Disease⁸¹.

One limitation of the review is that those people most likely to be socially isolated, for example, living in a care home, or who had poor cognition or severe aphasia, were often

systematically excluded from studies. Thus it is possible that this review underestimates the extent of social isolation and poor support post stroke.

In terms of significant associations between social support and other variables, the evidence was sometimes weak, with many associations assessed by only one or two studies. Another complicating factor, as noted also by the Kruithof et al.⁵ review, was the varied conceptions of social network and functional support (for example, received versus perceived; satisfaction versus availability). Other complicating factors included the varied timescales and different methodologies used.

At the review level, this report is, to our knowledge, the first comprehensive synthesis of research exploring functional support and social networks following a stroke. A strength of the review is the inclusion of both qualitative and quantitative studies. The literature search aimed to be as inclusive as possible. All papers were critically appraised, and one third of papers were selected for appraisal by two authors. Further, two authors were involved in the analysis of the qualitative studies. One limitation is that the search was restricted to the English language. There was also no consideration given to support received from professionals.

In terms of future directions, this review has shown the importance of social support in recovering from a stroke, and yet it is not known what factors predict who will feel well supported or who will have a strong social network post stroke. Although studies have examined predictors of the related concepts of social dysfunction⁸² and participation⁸³, no study has explored predictors of perceived social support or social network, as measured by a validated scale, in the stroke population. There is also a need for stroke studies to include

those most likely to be isolated, including facilitating the responses of those with aphasia and also those in residential homes.

There are a number of clinical implications. Firstly, the review found that people are at risk of losing contact with friends and social activities following a stroke, particularly those with aphasia, suggesting that therapy approaches that seek to support or enhance a person's social network may be of value. The review also found evidence of disharmony within the family unit, yet it is family members that are the main providers of functional support post stroke. In order to safeguard the quality of this support despite the strain of caregiving, it is arguably important to consider the family during rehabilitation, and explore family or couple-orientated interventions. The review also documented the close relationship between depression and poor social support; furthermore, in the qualitative reports a reason for reduced social participation was the sense that some participants were withdrawing and closing in on themselves. Enabling stroke survivors to want to re-engage once more is likely to improve both mood and a person's social functioning. Finally, those who are socially isolated at the time of the stroke appear to be at more risk of becoming depressed in the following months, and may therefore benefit from targeted support.

Clinical messages

1. Contact with friends and involvement in social activities was found to reduce post stroke
2. Contact with family was more stable, albeit with increased tension
3. Depression was consistently associated with poor social support and reduced social network following a stroke

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Table One. Details of included qualitative reports (n = 22)

	Included reports	Country	Time post onset mean (SD) or range	Number of participants	People with aphasia included	Research topic	Method
Aphasia and dysarthria studies	Brady et al. (2011) ²⁰	UK	8(7)mths	24	✗	Impact of dysarthria on social participation	Interviews
	Brown et al. (2010) ³³	Australia	71.5(62.3)mths	25	✓	Living successfully with chronic aphasia	Interviews
	Brown et al. (2013) ³⁷	Australia	71.5(62.3)mths	25	✓	Role of friendship in chronic aphasia	Interviews
	Dalemans et al. (2010) ³⁰	Netherlands	16mths–11yrs	13	✓	Social participation	Interviews + diary
	Davidson et al. (2008) ³⁶	Australia	9mths–9yrs	15	✓	Impact of aphasia on friendship	Observation + diary + video recall
	Fotiadou et al. (2014) ²⁷	Various	2 – 12 yrs	10	✓	Impact of aphasia on social relationships	Blog posts
	Grohn et al. (2012) ³⁸	Australia	3mths	15	✓	Living successfully with aphasia	Interviews
	Grohn et al. (2014) ³⁴	Australia	3, 6, 9, 12 mths	15	✓	Living successfully with aphasia over first year	Interviews
	Hinckley (2006) ¹⁹	Various	>2yrs	18	✓	Living successfully with aphasia	Published accounts
	Le Dorze & Brassard (1995) ²¹	Canada	2-14yrs	9	✓(✗severe)	Impact of aphasia using WHO model	Interviews
Parr et al. (1997) ²²	UK	>5yrs	50	✓(✗severe receptive)	Experiencing aphasia	Interviews	
Parr (2007) ⁴	UK	9mths–15yrs	20	✓ (only severe)	Social exclusion for those with severe aphasia	Ethnography	
General stroke studies	Anderson & Whitfield (2013) ³²	Canada	>5 yrs	9	✓(✗severe)	How family, social and community resources enhance participation	Interviews
	Ch'ng et al. (2008) ²³	Australia	4.4yrs(3.08)	26	✓ (? only mild)	Challenges of recovery; coping	Focus groups
	Dowswell et al. (2000) ²⁴	UK	13-16mths	30	Not specified	Psychosocial difficulties post stroke	Interviews
	Egbert et al. (2006) ²⁵	USA	>6mths post discharge	12	✗	Community re-integration post right-hemisphere stroke	Interviews
	Haun et al. (2008) ³¹	USA	1, 6, & 12mths	77	Not specified	Connectedness and isolation	Interviews
	Martinsen et al. (2012) ²⁸	Norway	6mths – 9 yrs	22	✓	Young stroke survivors' family life	Interviews
	Northcott & Hilari (2011) ³	UK	8–15mths	29	✓	Causes of friendship loss	Interviews
	Pallesen (2014) ²⁶	Denmark	5 yrs	15	✓(✗severe)	Perceptions of self-identity and disability	Interviews
	Pound et al. (1999) ²⁹	UK	10mths	40	✗severe	Social and practical strategies	Interviews
Sumathipala et al. (2012) ³⁵	UK	1-11yrs	35	✗severe	Long-term needs using ICF framework	Interviews	

Table Two. Details of included quantitative reports (n = 48)

	Included reports	Country	Time post onset, mean (s.d.) for x-sec	Number of pts	People with aphasia included	Research topic	Social support/ network measure
Aphasia stroke studies	Code et al. (2003) ⁷³	UK	36.5(29)mths	38	Y(proxy for severe receptive)	Relationship between social activity and aphasia	Social Network and Aphasia Profile
	Cruice et al. (2003) ⁶⁸	Australia	41(25.6)mths	30	Y(*severe receptive)	Relationship between communication, impairment, activity and participation with HRQL for people with aphasia	Social Network Analysis; Social Activities Checklist
	Cruice et al. (2006) ¹	Australia	41(25.6)mths	30	Y(*severe receptive)	Comparing people with aphasia's social contacts and social activities with age-matched controls	Social Network Analysis; Social Activities Checklist
	Hilari et al. (2003) ³⁹	UK	3.5(3.1)yrs	83	Y(*severe receptive)	Predictors of HRQL in people with aphasia	Social Support Survey
	Hilari & Northcott (2006) ⁴⁶	UK	3.5(3.1)yrs	83	Y(*severe receptive)	Relationship between social support and HRQL	Social Support Survey; Social network questions
	Vickers (2010) ⁵⁰	USA	81.4(45.8)mths	40	Y	Impact of stroke and aphasia on social networks	Social Networks Communication Inventory; Friendship Scale
General Stroke Population	Astrom et al. (1992) ⁴⁷	Sweden	T1:4-5d; T2:3mths	80	Y (proxy)	Living conditions and life satisfaction pre and post stroke	Single items from population survey
	Astrom et al. (1992) ⁸⁴	Sweden	T1: 4-5 days; T2:3mths; T3:1yr; T4:2yrs; T5:3yrs	80	Y(proxy)	Change over time in psychosocial function	As above
	Astrom et al. (1993) ⁶⁴	Sweden	As above	80	Y(proxy)	Predictors of depression; longitudinal course of depression	As above
	Astrom 1996 ⁸⁵	Sweden	As above	80	Y(proxy)	Predictors of generalised anxiety disorder (GAD); longitudinal course of GAD	As above
	Beckley (2007) ⁷⁴	USA	Range: 3-6mths post d/c	95	N	Impact of social support on community participation	Social Support Inventory for People with Acquired Disabilities
	Boden-Albala et al. (2005) ⁷²	USA	T1:4days; T1-4:annual, until 5 yrs	655	Y(proxy)	Relationship between social isolation and stroke outcomes	Single items
	Boynton de Sepulveda et al. (1994) ⁵²	USA	Range: 1-12mths	75	Not specified	Psychological stress and coping post stroke	Interpersonal Support Evaluation List; Lubben Social Network Scale
	Chau et al. 2010 ⁶⁵	China	6mths post d/c	210	N	Prevalence and predictors of depression	Social Support Questionnaire (SSQ6)
	Clark & Smith (1999) ²	Australia	T1:admission to rehab; T2:d/c from rehab; T3 & 4: 6&12mths post d/c	60	*severe	Changes in family functioning in stroke survivors and their families	Family Assessment Device
	Colantonio et al. (1993) ⁷¹	USA	T1: premorbid; T2:6 wks	87	Y	Relationship between pre-morbid psychosocial factors and physical function 6 weeks post stroke	Social Network Index
	Dayapoglu & Tan (2010) ⁶⁶	Turkey	>3mths	70	N	Relationship between quality of life and medical and socio-demographic variables	Perceived Social Support from the Family Scale
	Feibel & Springer (1982) ⁶³	USA	T1:10 days; T2:2mths; T3:6mths	91	Not specified	Factors associated with depression	Non-validated measure of social network
	Friedland & McColl (1987) ⁵³	USA	2-24mths post d/c from active rehabilitation	85	N	Social support as mediator between stress and psychosocial dysfunction post stroke	Social Support Inventory for Stroke Survivors
Glass & Maddox (1992) ⁷⁰	USA	T1:1mth; T2:3mths; T3:6mths	46	Y(proxy)	Impact of type and amount of support on physical recovery post stroke	Inventory of Socially Supportive Behaviours	
Glass et al. (1993) ⁸⁶	USA	As above	46	Y(proxy)	Impact of social support on physical outcome post stroke	Inventory of Socially Supportive Behaviours	

	Included reports	Country	Time post onset, mean (s.d.) for x-sec	Number of pts	People with aphasia included	Research topic	Social support/ network measure
General Stroke Population (con)	Griffen et al. (2009) ⁷⁷	USA	48.4(63.8)mths	90	N	Driving cessation and community integration	Social Provision Scale
	Hilari et al. (2010) ⁴⁰	UK	T1:2 wks; T2:3 mths; T3:6mths	87	Y(*severe receptive)	Predictors of psychological distress post stroke	Social Support Survey; Stroke Social Network Scale
	Hilari 2011 ⁸⁷	UK	As above	87	Y(*severe receptive)	Comparing people with and without aphasia post stroke on psychosocial outcomes	As above
	Huang et al. (2010) ⁶²	Taiwan	29.8(73.4)mths	102	N	Examining the associations between social support, depression and quality of life	Social Support Inventory
	King (1996) ⁴¹	USA	19(5.5)mths	86	Y(*severe)	Predictors of overall and domain specific quality of life	SSE
	King et al. (2002) ⁴⁵	USA	T1:d/c; T2:6-10wk post d/c; T3:1yr post d/c; T4:2yrs post d/c	97	Y(*severe)	Natural history of adaptation to stroke; predictors of stroke survivor and care-giver depressive symptoms	Family Assessment Device; Interpersonal Support Evaluation List
	Knapp & Hewison (1998) ⁴⁸	UK	T1:<1mth; T2:1mth post d/c; T3:6mths post d/c	30	N	Social support before and after stroke; relationship between social support and mood	Interview Schedule for Social Interaction
	Labi et al. (1980) ⁵¹	USA	Chronic	121	Not specified	Social reintegration of physically independent long-term stroke survivors	Non-validated measure of social network (socialisation in and out of house)
	Lam et al. (2010) ⁵⁴	China	Follow up appointment post d/c from hospital	50	N	Prevalence of depression; factors differentiating between those with and without depressive symptoms	Social Support Questionnaire (SSQ6)
	Lewin et al. (2013) ⁵⁸	Germany	6.64 (4.42) wks	96	N	Predictors of depression shortly after stroke onset	Social Support Questionnaire 22 item
	Li et al. (2003) ⁵⁵	Taiwan	28.9(31.5)mths	106	N	Prevalence and predictors of depression	Ming's social support scale
	Mackenzie et al. (2002) ⁶⁷	China	T1:≤48hrs; T2:2 wks; T3:3mths	215	N	Predictors of quality of life	Social Support Questionnaire SSQ6
	Morris et al. (1991) ⁵⁶	Australia	T1:approx. 2mths; T2: approx. 16mths	76	N	Relationship between social support and depression	Interview Schedule for Social Interaction
	Norris et al. (1990) ⁶⁹	USA	Range:2-13mths post d/c	48	Y(*severe)	Relationship between social supports, social problems and well being post discharge	Social Support Inventory
	Osberg et al. (1988) ⁸⁸	USA	T1:at admission; T2:12 mths post d/c	89	N	Exploring predictor variables on three long-term outcomes: functional status; life satisfaction; medical charges	Non-validated measure of SN (in and out of house social supports)
	Perry & McLaren (2004) ⁴²	UK	6 mths	206	Y(proxy)	The contribution of dietary and nutritional factors in relation to quality of life post stroke	Social Support Survey
	Rana et al. (2015) ⁷⁶	Germany & Pakistan	Acute	97	N	Determinants of coping styles; impact of culture on coping	Survey of Social Support (F-SozU)
	Robinson et al. (1983) ⁸⁹	USA	<2 weeks	103	Y(*severe)	Factors associated with depression in acute stage	Social Ties Checklist
	Shao et al. (2014) ⁷⁵	China	7.6 (6.20) yrs	214	N	How meaning in life mediates physical functioning, social support and optimism with subjective well-being	Social Support for Transactions
	Sharpe et al. (1994) ⁴⁹	UK	31–64mths	60	Y(proxy)	Prevalence and factors predictive of depression	Single items
Sit et al. (2007) ⁵⁷	China	T1:≤48 hrs; T2:6 mths	112	N	Associated factors of post stroke depression	Social Support Questionnaire - Transaction	
Stephens et al. (1987) ⁹⁰	USA	Range:2-13mths post d/c	48	Y(*severe)	Impact of social interactions on morale and cognitive functioning	Social Support Inventory	
Taylor-Piliae et al. (2013) ⁵⁹	USA	39 (49) mths	100	Not specified	Prevalence and predictors of depressive symptoms	Multidimensional Scale of Perceived Social Support (MSPSS)	
Townend et al. (2007) ⁶⁰	Australia	T1:2-5days; T2:1mth;	125	Y(*severe)	History, prevalence and determinants of mood disorder	Multidimensional Scale of Perceived Social	

	Included reports	Country	Time post onset, mean (s.d.) for x-sec	Number of pts	People with aphasia included	Research topic	Social support/ network measure
			T3:3mths			post stroke	Support
	Tsouna-Hadjis et al. (2000) ⁴³	Greece	T1:prior to d/c; T2:1mth; T3:3mths; T4:6mths	43	Y(proxy)	Role of family social support in functional status, depression and social status	Family Social Support Scale
	White et al. (2007) ⁴⁴	Australia	3 cohorts: 1, 3 and 5 yrs	90	Y(proxy)	Function and quality of life at 1, 3 and 5 years post stroke	Multidimensional Scale of Perceived Social Support
	White et al. (2014) ⁶¹	Australia	T1: <1wk; T2: 3mths; T3: 6mths; T4: 9mths; T5: 12mths	134	Y(*severe)	Predictors of depression and anxiety over 12-month period	Multidimensional Scale of Perceived Social Support

Abbreviations: T1: time one; T2: time two; T3: time three. d/c: discharge; wk: week; mth: month; yr: year. HRQL: health related quality of life

Figure One. Flow diagram illustrating the review process

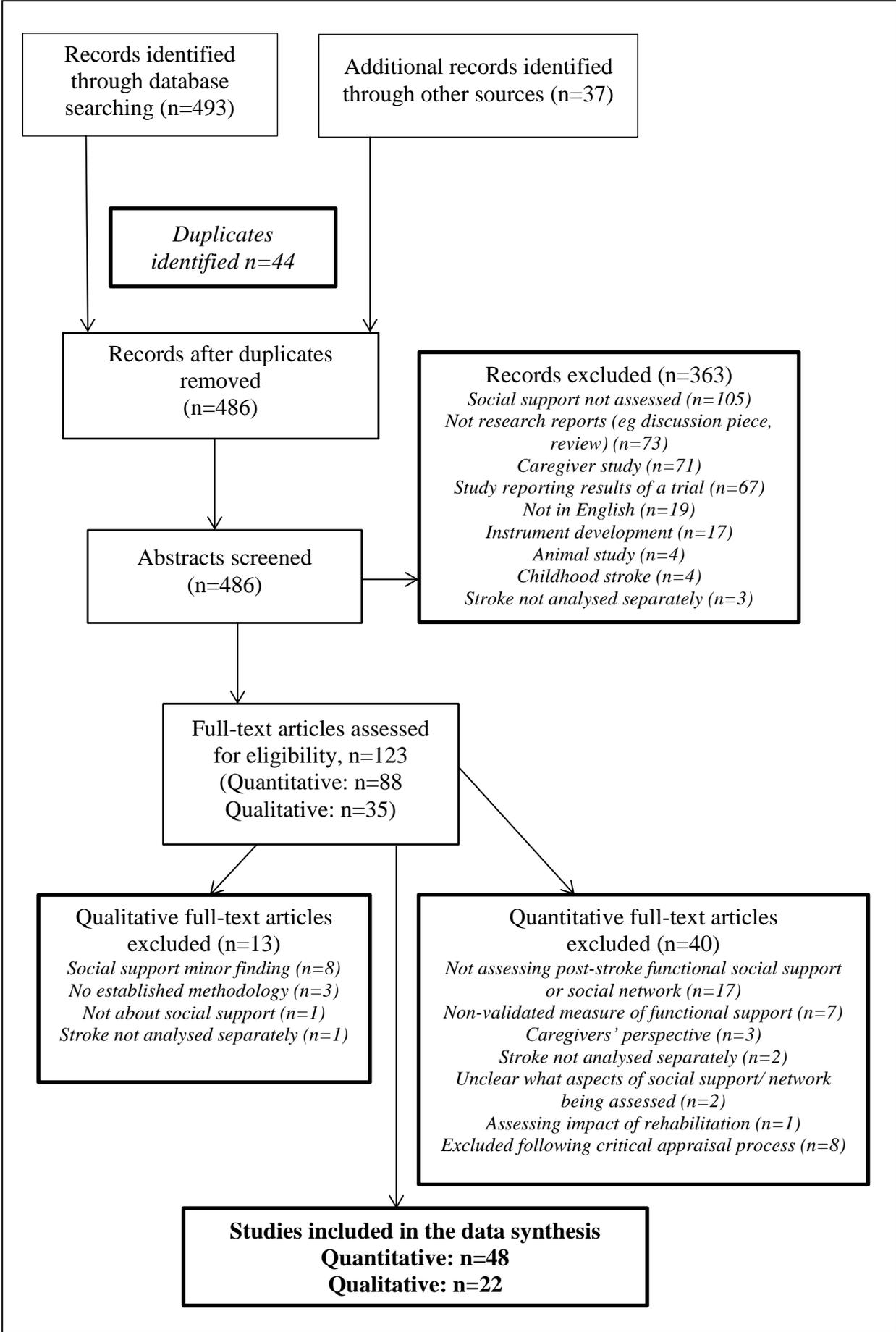


Figure Two. Summary of meta-ethnographic synthesis: impact of stroke on social support

Family life post stroke

- **Disruption to family relationships:** lost roles; changes to the daily routine; lost family activities; dealing with strong emotions; communication disability
- **Factors which make family life more harmonious:** being able to contribute and maintain roles; negotiating support and independence; being able to express and receive intimacy and love

Friends, acquaintances and social participation

- **Difficulties in maintaining friends and social activities:** lost friends; fewer social activities; loneliness
- **Perceived causes of reduced participation:** disability; fatigue; relocation; environmental barriers; lost activities; financial; internal barriers; communication difficulties; stigma
- **A new selectivity/changing social preferences**
- **Factors which facilitate social participation:** attitude of stroke survivor; support from family; nature of pre-stroke friendships

The value of social relationships and support

- **Perceived value of friendships and social activities:** including role of new friends; peer support e.g. via stroke groups
- **Valued social support functions:** including emotional support, e.g. feeling valued and accepted; companionship support; support that fosters independence

Figure Three. Valued support functions

Summary of social support functions found to be most valued following a stroke.

- Feeling valued and loved
- Encouragement; others believing in them; solidarity
- Constancy; knowing someone is there
- Acceptance and understanding; reassurance
- Receiving needed tangible care in a way that fosters competence
- Helping to promote independence, a sense of control, and social participation
- Social companionship including humour, distraction, spending positive time with family and friends
- Being able to make a contribution/ maintain roles
- Meeting other stroke survivors

Figure Four. Relationship between functional support, social network and other variables

Functional social support

- + **Depression/ depressive symptoms:** 13/14 studies found significant association
- + **HRQL:** 6/6 studies found either subscale or overall functional support significantly associated
- + **Physical recovery:** 2/2 studies found significant association with emotional support
- **ADL:** 4/5 studies found no significant association with concurrent ADL
- **Aphasia (severity/presence):** 2/2 studies found no significant association
- **Cognition:** 2/3 studies found no significant association with concurrent cognition

Social network

- + **Depression:** 7/8 studies (specific aspects, e.g. contact with friends; *not* size of network)
- + **HRQL:** 3/3 studies (one study, for women only; one study, specific HRQL domains only)
- + **Disability (severity of disability in chronic phase):** 2/2 studies found significant association
- + **Aphasia (severity):** 2/2 studies found significant association

Key: + most/all studies found significant association; - most/all studies found no significant association

Appendix A. Search strategy employed.

Date of search: July 2013; search then re-run 19th May 2015.

Databases searched: Academic Search Complete; CINAHL Plus; E-journals; Health Policy Reference Centre; MEDLINE; PsycARTICLES; PsycINFO; and SocINDEX using EBSCOHost.

Search Options:

Search Modes and Expanders:

- Search modes: Boolean/ phrase
- 1. Field: Title. Search terms: ‘stroke’ OR ‘aphasia’
AND
- 2. Field: Abstract. Search terms: ‘social support’ OR ‘social network’ OR ‘social activity’ OR ‘social satisfaction’ OR ‘lonel*’ OR ‘social participation’
- Results limited by: Scholarly (peer reviewed journals); Published data; Language: English
- No other limiters E.g. published date: unrestricted; E.g. number of pages: ALL; E.g. geographical region: ALL

Copy of search strategy for PsycINFO (run on 19th May 2015):

#	Query	Limiters/Expanders	Last Run Via	Results
S1	TI (‘stroke’ OR ‘aphasia’) AND AB (‘social support’ OR ‘social network’ OR ‘social activity’ OR ‘social satisfaction’ OR ‘lonel*’ OR ‘social participation’)	Limiters - Peer Reviewed; Publication Type: Peer Reviewed Journal; English; Language: English; Exclude Dissertations Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - PsycINFO	322

Appendix B. Qualitative reports: critical appraisal (n = 22)

	Studies recruiting participants with communication disabilities only							
	Brady et al. (2011)	Brown et al. (2010)	Brown et al. (2013)	Dalemans et al. (2010)	Davidson et al. (2008)	Fotiadou et al. (2014)	Grohn et al. (2012)	Grohn et al. (2014)
Quality assessment								
1 Clearly focused RQ	✓	✓	✓	✓	✓	✓	✓	✓
2 Qualitative methodology appropriate	✓	✓	✓	✓	✓	✓	✓	✓
3 Research design justified	✓	✓	✓	✓	✓	✓	✓	✓
4 Recruitment strategy								
Recruitment process explained/justified	✓ purposive	✓ purposive	✓ purposive	✓ purposive	✓	✓	✓	✓
Participants appropriate for RQ	✓	✓ (stroke group attendees / on university register)	✓ (stroke group attendees / on university register)	✓ (needed willing care-giver)	✓	✓ (young, computer literate)	✓	✓
5 Data collection								
Method selected (eg focus group, in-depth interview, published data)	Semi-structured interviews	Interviews + participant photos	Interviews + participant photos	Diary + semi-structured interviews	Observation + diary + stimulated recall interview	Blog posts	Semi-structured interview	Semi-structured interview
Data collected in a way that addresses RQ	✓	✓	✓	✓	✓	✓	✓	✓
Methods used clearly explained	✓	✓	✓	✓	✓	✓	✓	✓
Saturation of data discussed				✓				
6 Researcher/ participant relationship								
Researcher considered own influence	Not considered	✓	✓	✓	✓	Not considered	Not considered	✓
7 Ethical issues								
Consideration of ethical issues	✓	✓	✓	✓	✓	✓	✓	✓
Approval from ethics committee	✓	✓	✓	✓	✓	✓	✓	✓
8 Data analysis								
Analytic method used (where specified)	Grounded theory	Interpretative Phenomenological Analysis	Interpretative Phenomenological Analysis			Framework	Thematic analysis	Thematic
In-depth description of analysis process	No	✓	✓	✓	✓	✓	✓	✓
Rigour (clarity as to how themes derived; sufficient data presented)	✓	✓	✓	✓	✓	✓	✓	✓
Contradictory data considered		✓	✓	✓	✓	✓	✓	✓
9 Findings								

Clear statement of findings		✓	✓	✓	✓	✓	✓	✓
Credibility discussed	✓ (>1 analyst)	✓ >1 analyst; audit trail	✓ >1 analyst; audit trail	✓ respondent validation; >1 analyst	✓ triangulation + respondent validation	✓ >1 analyst	✓ >1 analyst	✓ audit trail; >1 analyst
10 Value of the research								
Contribution to knowledge discussed	✓	✓	✓	✓	✓	✓	✓	✓
Transferability of findings discussed	✓ (not severe dysarthria, nor those with depression)	Specific to group attendees with mild-moderate aphasia?	Specific to group attendees with mild-moderate aphasia?	✓ (findings relate only to those living with partner?)	✓ (3 took part in video recall)	specific to younger, computer literate people with aphasia?	✓	✓ (mild-moderate aphasia)

Appendix B con p2/3	Studies recruiting participants with communication disabilities only				Participants with and without communication disabilities		
	Hinckley et al. (2006)	Le Dorze & Brassard (1995)	Parr et al. (1997)	Parr (2007)	Anderson & Whitfield (2012)	Ch'ng et al. (2008)	Dowswell et al. (2000)
Quality assessment							
1 Clearly focused RQ	✓	✓	✓	✓	✓	✓	
2 Qualitative methodology appropriate	✓	✓	✓	✓	✓	✓	✓
3 Research design justified	✓	✓	✓	✓	✓	✓	✓
4 Recruitment strategy							
Recruitment process explained/justified	✓	✓	✓ purposive	✓ purposive	✓ purposive	✓	✓
Participants appropriate for RQ	Not representative (younger, well-educated)	✓ needed willing care-giver; members of aphasia association	✓	✓	✓ (aged 53-64)	✓ (through stroke groups only)	Limited participant info
5 Data collection							
Method selected (eg focus group, in-depth interview, published data)	Published accounts written by people with aphasia	Semi-structured interviews	Semi-structured interviews	Ethnography	Semi-structured interviews	Focus groups	Semi-structured interviews
Data collected in a way that addresses RQ	✓	✓	✓	✓	✓	✓	✓
Methods used clearly explained	✓	✓	✓	✓	✓	✓	✓
Saturation of data discussed					✓	✓	
6 Researcher/ participant relationship							
Researcher considered own influence	✓	Not considered	Not considered	✓	Not considered	Not considered	Not considered
7 Ethical issues							
Consideration of ethical issues	N/A	✓	✓	✓	✓		✓
Approval from ethics committee	N/A		✓		✓		
8 Data analysis							
Analytic method used (where specified)			Framework	Framework	Grounded theory/situational analysis	Grounded theory	
In-depth description of analysis process		✓	✓	✓	✓	✓	✓
Rigour (clarity as to how themes derived from data; sufficient data presented)		✓	✓	✓	✓	✓	✓

Contradictory data taken into account		✓	✓	✓	✓	✓	✓
9 Findings							
Clear statement of findings	✓	✓	✓	✓	✓	✓	✓
Credibility discussed	✓ >1 analyst	✓ > 1 analyst	one main analyst?	✓ respondent validation	✓ (>1 analyst)	✓ respondent validation	✓ 2 analysts
10 Value of the research							
Contribution to knowledge discussed	Brief	✓	✓	✓	✓	✓	✓
Transferability of findings discussed	Specific to those who are well-educated and young?	✓ (specific to those who seek to belong to Aphasia Association?)	✓	✓	✓ (narrow age range)	Specific to stroke group attendees?	Limited participant info

Appendix B con p3/3	Studies recruiting people with and without communication disabilities						
	Egbert et al. (2006)	Haun et al. (2008)	Martinsen et al. (2012)	Northcott & Hilari (2011)	Pallesen (2014)	Pound et al. (1999)	Sumathipala et al. (2011)
Quality assessment							
1 Clearly focused RQ			✓	✓		✓	✓
2 Qualitative methodology appropriate	✓	✓	✓	✓	✓	✓	✓
3 Research design justified	✓	✓	✓	✓	✓	✓	✓
4 Recruitment strategy							
Recruitment process explained/justified	✓	No	✓	✓ purposive	✓ purposive	✓ consecutive	✓
Participants appropriate for RQ	✓ Through stroke groups and conferences. Needed willing care-giver	Men only; limited participant info	✓ (only 2 needed help with ADL)	✓ (through larger study)	✓	✓	✓
5 Data collection							
Method selected (eg focus group, in-depth interview, published data)	Semi-structured interviews	Semi-structured interviews	Semi-structured interviews	Semi-structured interviews	Semi-structured interviews	Semi-structured interviews	Semi-structured interviews
Data collected in a way that addresses RQ	✓	Retrospective	✓	✓	✓	✓	✓
Methods used clearly explained	✓		✓	✓	✓	✓	✓
Saturation of data discussed	✓		✓				
6 Researcher/ participant relationship							
Researcher considered own influence	✓	Not considered	Not considered	Not considered	✓	Not considered	Not considered
7 Ethical issues							
Consideration of ethical issues raised by study			✓	✓	✓	✓	✓
Approval from ethics committee			✓	✓	✓		✓
8 Data analysis							
Analytic method used	Grounded theory		Interpretative Phenomenological Analysis	Framework		Grounded theory	
In-depth description of analysis process	✓	✓	✓	✓	✓	✓	✓
Rigour (clarity as to how themes derived from data; sufficient data presented)	✓	✓	✓	✓	✓	✓	✓
Contradictory data taken into account	✓		✓	✓	✓		
9 Findings							
Clear statement of findings	✓		✓	✓	✓	✓	

Credibility discussed	✓ 4 analysts; respondent validation	2 analysts for coding only	✓ (research findings discussed in team)	One main analyst	One main analyst	One main analyst?	2 analysts for coding only
10 Value of the research							
Contribution to knowledge discussed		✓	✓	✓	✓	✓	✓
Transferability of findings discussed	Specific to stroke group attendees with care-giver? More men (n = 10) than women (n =2)	Men only; limited participant info	✓ (only 2 participants needed help with ADL)	✓	✓	Specific socio-economic group	✓

Appendix C. Details of studies excluded following critical appraisal process

Publication details	Reason for exclusion
Adeniyi, A., O. Idowu, O. Ogwumike, and C. Adeniyi. (2012). Comparative influence of self-efficacy, social support and perceived barriers on low physical activity development in patients with type 2 diabetes, hypertension or stroke. <i>Ethiop J Health Sci</i> 22:113-9.	Age and gender details for stroke participants not reported separately
Belanger, L., M. Bolduc, and M. Noel. (1988). Relative importance of after-effects, environment and socio-economic factors on the social integration of stroke victims. <i>Int J Rehabil Res</i> 11:251-60.	Extensive exclusion criteria
Chang, A., A. E. Mackenzie, M. Yip, and R. Dhillon. 1999. The psychosocial impact of stroke. <i>Journal of Clinical Nursing</i> 8:477-481.	Age and gender details not reported
Glymour, M. M., J. Weuve, M. E. Fay, T. Glass, and L. F. Berkman. 2008. Social ties and cognitive recovery after stroke: does social integration promote cognitive resilience? <i>Neuroepidemiology</i> 31:10-20.	Extensive exclusion criteria
Kim, P., S. Warren, H. Madill, and M. Hadley. 1999. Quality of life of stroke survivors. <i>Qual Life Res</i> 8:293-301	Poor response rate (<50% for face to face)
Kishi, Y., R. G. Robinson, and J. T. Kosier. 1996. Suicidal plans in patients with stroke: comparison between acute-onset and delayed-onset suicidal plans. <i>Int Psychogeriatr</i> 8:623-34.	Poor follow up rate (>50% lost to follow up over 2 years)
Michael, K. M., J. K. Allen, and R. F. Macko. 2006. Fatigue after stroke: relationship to mobility, fitness, ambulatory activity, social support, and falls efficacy. <i>Rehabil Nurs</i> 31:210-7.	Extensive exclusion criteria
Teoh, V., J. Sims, and J. Milgrom. 2009. Psychosocial predictors of quality of life in a sample of community-dwelling stroke survivors: a longitudinal study. <i>Top Stroke Rehabil</i> 16:157-66.	Poor response rate (<20% for postal)

Appendix D. Critical appraisal of included quantitative reports (n = 48)

Appendix D; p1/3	Aphasia stroke studies						General stroke studies									
	Code et al. (2003)	Cruice et al. (2003)	Cruice et al. (2006)	Hilari et al. (2003)	Hilari & Northcott (2006)	Vickers et al. (2010)	Astrom et al. (1992A)	Astrom et al. (1992B)	Astrom et al. (1993)	Astrom (1996)	Beckley (2007)	Boden-Albala et al. (2005)	Boynton De Sepulveda et al. (1994)	Chau et al. (2010)	Clark & Smith (1999)	Colantonio et al. (1993)
Quality assessment																
1 Clearly focused RQ	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✗	✓	✓	✓
2 Appropriate methodology for RQ	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
3 Cohort/ sample recruitment																
Community based	✓ (charity)	✓	✓	✓	✓	✓ (university)	Stroke unit	Stroke unit	Stroke unit	Stroke unit	Rehab	Popula- tion	Rehab records	Rehab	Rehab unit	Hospital
No major exclusion criteria	✓	✗↓mobility ✗<55 yrs	✗↓mobility ✗<55 yrs	✓	✓	✓	✓ (TIAs ✓)	✓ (TIAs ✓)	✓ (TIAs ✓)	✓ (TIAs ✓)	✓	✗haemor- -rhage	✗≤ 62 yrs	✓	✗live alone ✗<2 wks rehab	✓
TPO stated	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	Post d/c	✓	1-12 mths	Post d/c	Post d/c	✓
4 Exposure accurately measured																
Valid, reliable assessment of social support/network	✗SN	SN✓ ✗ Soc Act	SN✓ ✗ Soc Act	✓	✓SS ✗SN	✓	✗	✗	✗	✗	✓	✗	✓	✓	✓	✓SN ✗SS
5 Outcomes accurately measured																
Valid, reliable assessment of other measures	✓	✓	N/A	✓	✓	✗	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
6 Confounding factors identified																
Stroke severity considered	✗	✗	✗	✗	✗	✗	✗	✗	✗	✗	✗	✓	✗	✗	✗	✓
Confounding factors taken account of	✓	✓	✓	✓	✗	✓	✓	✗	✓	✓	✓	✓	✓	✓	✗	✓
7 Follow up (% lost to follow up)	N/A	N/A	N/A	N/A	N/A	N/A	39% lost	5% lost	39% lost	39% lost	N/A	2% lost	N/A	N/A	26%	21% lost
>30 days	N/A	N/A	N/A	N/A	N/A	N/A	✓	✓	✓	✓	N/A	✓	N/A	N/A	✓	✓
Fixed points used	N/A	N/A	N/A	N/A	N/A	N/A	✓	✓	✓	✓	N/A	✓	N/A	N/A	✓	✓
8 Results of the study relevant to review	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
9 CIs reported	✗	✗	✗	✗	✗	✗	✗	✗	✗	✗	✗	✓	✗	✓	✗	✗
10 Reliable results	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
11 Applicability of results																
Age details provided	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Sex details provided	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓

Appendix D (con); p2/3	Dayapoglu & Tan (2010)	Feibel & Springer (1982)	Friedland & McColl (1987)	Glass & Maddox (1992)	Glass et al. (1993)	Griffen et al. (2009)	Hilari et al. (2010)	Hilari (2011)	Huang et al. (2010)	King (1996)	King et al. (2002)	Knapp & Hewison (1998)	Labi et al. (1980)	Lam et al. (2010)	Lewin et al. (2013)	Li et al. (2003)
Quality assessment																
1 Clearly focused RQ	✓	✗	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✗	✓	✓	✓
2 Appropriate methodology for RQ	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✗	✓	✓	✓
3 Cohort/ sample recruitment																
Community based	Neurology OP clinic	Hospital	Hospital	Hospital	Hospital	✓	Stroke unit	Stroke unit	Hospital OP	Hospital	Rehab unit	Hospital	?	Day clinic	Neuro rehab centre	Hospital OP
No major exclusion criteria	✓	✗full recovery in 2 mths	✗>65 ✗<25	✗haemo-rrhage	✗haemorrhage	✗non-driver pre-stroke	✓	✓	✗haemorrhage	✓	✗living alone	✗no willing caregiver	✗ ADL dependent	✗<65 yrs	✗haemorrhage ✗co-morbidities	✗<65 yrs ✗↓mobility
TPO stated	>3 mths	✓	✗	✓	✓	✓	✓	✓	✓	✓	Post d/c	✓	✗	✗	✓	✓
4 Exposure accurately measured																
Valid, reliable assessment of social support/network	✓	✗	✓	✓	✓	✓	✓SS ✗ SN	✓	✓	✓	✓	✓	✗	✓	✓	✓
5 Outcomes accurately measured																
Valid, reliable assessment of other measures	✓	✗	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✗	✓	✓	✓
6 Confounding factors identified																
Stroke severity considered	✗	✗	✗	✓	✓	✗	✓	✓	✗	✗	✗	✗	✗	✗	✗	✗
Confounding factors taken into account	✗	✗	✓	✓	✓	✓	✓	✓	✓	✓	✓	✗	✓	✗	✓	✓
7 Follow up (% lost to follow up)	N/A	27%	N/A	?	?	N/A	18%	18%	N/A	N/A	45% lost	0%	N/A	N/A	N/A	N/A
>30 days	N/A	✓	N/A	✓	✓	N/A	✓	✓	N/A	N/A	✓	✓	N/A	N/A	N/A	N/A
Fixed points used	N/A	✓	N/A	✓	✓	N/A	✓	✓	N/A	N/A	✓	✓	N/A	N/A	N/A	N/A
8 Results of the study relevant	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
9 CIs reported	✗	✗	✗	✗	✗	✗	✓	✗	✗	✗	✗	✗	✗	✗	✗	✗
10 Reliable results	✗ (multiple comparisons)	✗ (over reliance on non-validated scales)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✗ (over reliance on non-validated scales)	✓	✓	✓
11 Applicability of results																
Age details provided	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	Reported elsewhere	✓	✓	✓
Sex details provided	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	Reported elsewhere	✓	✓	✓

Appendix D (con) p 3/3	Mackenzie et al. (2000)	Morris et al. (1991)	Norris et al. (1990)	Osberg et al. (1988)	Perry & MacLaren (2004)	Rana et al. (2015)	Robinson et al. (1983)	Shao et al. (2014)	Sharpe et al. (1994)	Sit et al. (2007)	Stephens et al. (1987)	Taylor-Piliae et al. (2013)	Townsend et al. (2007)	Tsouana-Hadjis et al. (2000)	White et al. (2007)	White et al. (2014)
Quality assessment																
1 Clearly focused RQ	✓	✓	✓	✓	✓	✓	✗	✓	✓	✓	✓	✓	✓	✓	✓	✓
2 Appropriate methodology for RQ	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✗	✓
3 Cohort/ sample recruitment																
Community based	Rehab	Rehab	Rehab	Rehab	Hospital	Hospital	Hospital	Community health centres	Population	Rehab	Rehab	✓	Hospital	Hospital	Hospital	Stroke units
No major exclusion criteria	✓	✗no-one to turn to	✓	✗mild stroke	✓	✓	✓	✗<60 yrs	✓ (TIA✓)	✓	✓	✗<50 yrs ✗very mild/severe stroke	✓	✓	✓	✓
TPO stated	✓	✓	Post d/c	Post d/c	✓	✗	✓	✓	✓	✓	Post d/c	✓	✓	✓	✓	✓
4 Exposure accurately measured																
Valid, reliable assessment of social support (SS)/network (SN)	✓	✓	✓	✗	✓	Psychometrics of Pakistani translation not provided	✓	✓	✗	✓	✓	✓	✓	✓	✓	✓
5 Outcomes accurately measured																
Valid, reliable assessment of other measures	✓	✓	✓	✗	✓	✗	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
6 Confounding factors identified																
Stroke severity considered	✗	✗	✗	✓	✗	✗	✗	✗	✗	✓	✗	✗	✓	✓	✓	✗
Other confounding factors	✓	✓	✓	✓	✓	✓	✗	✓	✓	✓	✓	✓	✓	✓	✗	✓
7 Follow up (% lost to follow up)	26% lost	42% lost	N/A	Not specified	N/A	N/A	N/A	N/A	N/A	15%	N/A	N/A	17%	14% lost	N/A	18%
>30 days	✓	✓	N/A	✓	N/A	N/A	N/A	N/A	N/A	✓	N/A	N/A	✓	✓	N/A	✓
Fixed points used	✓	✓	N/A	✓	N/A	N/A	N/A	N/A	N/A	✓	N/A	N/A	✓	✓	N/A	✓
8 Results of the study relevant	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
9 CIs reported	✗	✗	✗	✗	✗	✗	✗	✗	✓	✗	✗	✗	✓	✗	✗	✓
10 Reliable results	✓	✓	✓	✗ (over-reliance on non-validated scales)	✓	✗ (No response rate provided; validity of translated measures unconfirmed)	✓	✓	✗ (poor event to IV ratio in multiple regression)	✓	✗ (multiple comparisons)	✓	✓	✓	✗ (small sample size for comparing groups)	✓
11 Applicability of results																
Age details provided	✓	✓	✓	Reported elsewhere	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Sex details provided	✓	✓	✓		✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓

Appendix D Abbreviations: ADL: activities of daily living; d/c: discharge; IV: independent variable; ↓mobility: impaired mobility; mth: month; OP: outpatient; rehab: rehabilitation; RQ: research question; SN: social network; Soc Act: social activities; SS: social support; TIA: transient ischaemic attack; wks: weeks; yrs: years

Appendix E. Summary of results: what happens to social support/ network, and significant associations (n = 48)

		Descriptives								Associations with other factors											
Included reports		Functional social support		Social network						Functional social support						Social network					
		Good/high	Stable over time	Contact with children stable	Contact with close attachment figures stable	Family functioning deteriorated	Size of network reduced / less than controls	Reduction in friends/ less than controls	Reduction in social activities/ less than controls	Depression/ depressive symptoms	HRQL	ADL/ disability	Recovery	Severity of aphasia	Cognition	Depression/ depressive symptoms	HRQL	ADL/ disability	Recovery/ future adverse event	Severity of aphasia	Cognition
Aphasia stroke studies	Summary of results	6/6	4/4	2/2	2/2	2/2	2/2	5/5	3/3	13/14	6/6	2/5	2/2	0/2	1/3	7/8	3/3	2/2	2/2	2/2	-
	Code et al. (2003) ⁷³																	✓#		✓✓#	
	Cruice et al. (2003) ⁶⁸																✓✓ ^y			✓#	
	Cruice et al. (2006) ¹						✓	✓	✓												
	Hilari et al. (2003) ³⁹	✓									[x]										
	Hilari & Northcott (2006) ⁴⁶	[✓]		✓					✓		✓#			x			✓#				
General Stroke Population	Vickers (2010) ⁵⁰						✓	✓	✓												
	Astrom et al. (1992) ⁴⁷			✓				✓	✓												
	Astrom et al. (1992) ⁸⁴							[✓]	[✓]												
	Astrom et al. (1993) ⁶⁴															✓✓#					
	Astrom 1996 ⁸⁵															✓✓#					
	Beckley (2007) ⁷⁴																		✓✓#		
	Boden-Albala et al. (2005) ⁷²									✓		x				✓					
	Boynton de Sepulveda et al. (1994) ⁵²																				
	Chau 2010 ⁶⁵															x#					
	Clark & Smith (1999) ²						✓														
	Colantonio et al. (1993) ⁷¹																		✓✓		
	Dayapoglu & Tan (2010) ⁶⁶										✓										
	Feibel & Springer (1982) ⁶³																				
	Friedland & McColl (1987) ⁵³									✓✓											
	Glass & Maddox (1992) ⁷⁰													✓							
	Glass et al. (1993) ⁸⁶												[✓]								
	Griffen et al. (2009) ⁷⁷																				
Hilari et al. (2010) ⁴⁰	✓	✓								✓✓					✓✓#						
Hilari 2011 ⁸⁷	[✓]	[✓]												x							
Huang et al. (2010) ⁶²										x	✓#	✓#									

	Included reports	Descriptives								Associations with other factors											
		Functional social support		Social network						Functional social support					Social network						
		Good/high	Stable over time	Contact with children stable	Contact with close attachment figures stable	Family functioning deteriorated	Size of network reduced / less than controls	Reduction in friends/ less than controls	Reduction in social activities/ less than controls	Depression/ depressive symptoms	HRQL	ADL/ disability	Recovery	Severity of aphasia	Cognition	Depression/ depressive symptoms	HRQL	ADL/ disability	Recovery/ future adverse event	Severity of aphasia	Cognition
King (1996) ⁴¹	✓									✓✓											
King et al. (2002) ⁴⁵		✓			✓				✓✓						✓✓#						
Knapp & Hewison (1998) ⁴⁸				✓			✓								✓#						
Labi et al. (1980) ⁵¹								✓									✓#				
Lam et al. (2010) ⁵⁴										✓					✓						
Lewin et al. (2013) ⁵⁸									✓✓		✓		✓								
Li et al. (2003) ⁵⁵									✓#												
Mackenzie et al. (2002) ⁶⁷										✓✓											
Morris et al. (1991) ⁵⁶									✓		×		×		✓						
Norris et al. (1990) ⁶⁹											×		×								
Osberg et al. (1988) ⁸⁸																					
Perry & McLaren (2004) ⁴²	✓									✓✓											
Rana et al. (2015) ⁷⁶																					
Robinson et al. (1983) ⁸⁹															✓						
Shao et al. (2014) ⁷⁵																					
Sharpe et al. (1994) ⁴⁹				✓											✓#						
Sit et al. (2007) ⁵⁷										✓✓#											
Stephens et al. (1987) ⁹⁰																					
Taylor-Piliae et al. (2013) ⁵⁹										✓✓											
Townend et al. (2007) ⁶⁰										✓✓											
Tsouna-Hadjis et al. (2000) ⁴³	✓	✓								✓#		✓									
White et al. (2007) ⁴⁴	✓	✓																			
White et al. (2014) ⁶¹										✓✓											

Key: ✓ significant in univariate analysis; ✓✓ significant in multivariate analysis; × no significant relationship; ✓#/×# specific function of support/ aspect of social network associated/not associated only; [✓]/[×]: results from same sample reported in two papers; † aspects of social network associated with specific subdomains of HRQL only

Appendix F. What happens to social support and social network following a stroke? (19 reports based on 16 studies)

	SUMMARY OF RESULTS	Cruice et al. (2006)	Hilari et al. (2003)	Hilari & Northcott (2006)	Vickers (2010)	Astrom et al. (1992)	Astrom et al. (1992)	Chau et al. (2010)	Clark & Smith (1999)	Hilari et al. (2010)	Hilari (2011)	King (1996)	King et al. (2002)	Knapp & Hewison (1998)	Labi et al. (1980)	Lam et al. (2010)	Perry & McLaren (2004)	Sharpe et al. (1994)	Tsouana-Hadjis et al. (2000)	White et al. (2007)
Functional social support																				
Good/ high	6/6		✓	(✓)						✓	(✓)	✓					✓		✓	✓
Stable over time	4/4									✓	(✓)		✓						✓	✓
Satisfied	2/3							✓				✓				*only 'a little satisfied'				
Social Network																				
Size																				
Reduced post stroke	1/1				✓															
Less than controls	1/1	✓																		
Family: overall																				
Family functioning deteriorated since stroke	2/2								✓				✓							
% 'dysfunctional' families post stroke	33-58%								58.3%				33%							
Availability of close, attachment relationship	2/2													✓				✓		
Children																				
Frequency of contact stable	2/2			✓		✓	(✓)													
Contact comparable to controls	1/1					✓	(✓)													
Other relatives																				
Frequency of contact reduced post stroke	2/2			25% less; 42% same	✓*	✓*														
Contact less than controls	1/1					✓*														
Friends and other social contacts																				
Number reduced since stroke	2/2				✓*															
Number less than controls	2/2	✓				✓*	(✓*)							✓						
Frequency of contact reduced post stroke	3/3			✓	✓*	✓*	(✓*)													
Social activities/ groups																				
Number reduced since stroke	3/3					✓	✓								✓					
Number less than controls	1/1	✓																		
Dissatisfied compared to controls	1/1	✓																		

*Friends and relatives analysed together (✓) results from single study reported in two papers

Appendix G. Relationship between social support/network and depression or depressive symptoms after a stroke (21 reports based on 20 studies)

	SUMMARY OF RESULTS	Astrom et al. (1993)	Astrom et al. (1996)	Boynton De Sepulveda & Chang (1994)	Chau et al. (2010)	Feibel & Springer (1982)	Friedland & McColl (1987)	Hilari et al (2010)	Huang et al. (2010)	King et al. (2002)	Knapp & Hewison (1998)
Depression											
Social support (SS) associated with depression/depressive symptoms	13/14			✓ (except for those severely disabled)	✓✓		✓✓ Satisfaction	* at 2 weeks ✓✓ at 3 mths ✓ at 6 mths	*SS (however, Tangible SS partially mediates association between ADL and depression)	✓✓ at d/c: SS ✓✓ 2yrs: belonging ✓ 2yrs: SS	
T1 SS associated with T2 depression/depressive symptoms	3/5							*		✓✓ belonging SS	
SS distinguishes depressed vs non-depressed	1/1						✓ (Satisfaction; quality)				
Social network (SN) associated with depression/depressive symptoms	7/8	✓✓ (at d/c) living alone ✓✓ (3mth – 3 yrs) few social contacts	[✓✓ (at d/c) living alone ✓✓ (3mth – 3 yrs) few social contacts]	✓	* quantity			* size of network at 2 wks, 3&6 mths * satisfaction at 2 wks ✓ satisfaction at 3 mths ✓✓ satisfaction at 6 mths		✓✓ 2yrs: family functioning ✓✓ 2yrs: satisfaction with quantity	✓ 1 & 6 mths: attachment relationship *satisfaction reln ✓ 1mth: wider network *6mth: wider network & satisfaction network
T1 SN associated with T2 depression/depressive symptoms	2/2							✓✓ satisfaction with social network			✓ 3mths/*6mths attachment relationship *satisfaction reln ✓ 3&6mths: wider network *satisfaction network
SN distinguishes depressed vs non-depressed	2/2					✓ (social activities)	✓ (personal; relative/friends; community) *overall quantity				

✓significant in univariate analysis; ✓✓ significant in multivariate analysis (DV: depression/depressive symptoms); *no significant relationship
d/c: discharge; SS: Social support; SN: social network; T1: time one; T2: time two; [] results from same study reported in two papers

Appendix G; con p2/2 (see p1/2 above for summary of results)	Lam et al. (2010)	Lewin et al. (2013)	Li et al. (2003)	Morris et al. (1991)	Robinson et al. (1983)	Sharpe et al. (1994)	Sit et al. (2007)	Taylor-Piliae et al. (2013)	Townend et al. (2007)	Tsouna-Hadjis et al. (2000)	White et al. (2014)
Depression											
SS associated with depression/ depressive symptoms	✓	✓✓	✓ Emotional ✓ Information ✓ Affirmation *Tangible	✓			✓✓ Social companionship ✓✓ Informational *Emotional *Tangible	✓✓	✓✓ (at 1 & 3 mths)	✓ Emotional * Compliance * Tangible	✓ (at 3, 6, 9, 12 mths f/u)
T1 SS associated with T2 depression/ depressive symptoms				✓ (poor T1 SS associated with longer lasting depression)						*	✓ (resolution of depression at 12 mths associated with BL SS)
SS distinguishes depressed vs non-depressed											
SN associated with depression/ depressive symptoms	✓				✓	✓having close personal relationship					
T1 SN associated with T2 depression/ depressive symptoms											
SN distinguishes depressed vs non-depressed											

✓significant in univariate analysis; ✓✓ significant in multivariate analysis (DV: depression/depressive symptoms); *no significant relationship
d/c: discharge; SS: Social support; SN: social network; T1: time one; T2: time two

Appendix H. Relationship between health-related quality of life (HRQL) and social support/network after a stroke (8 reports based on 7 studies)

	SUMMARY OF RESULTS	Cruice et al. (2003)	Hilari et al. (2003)	Hilari & Northcott (2006)	Dayapoglu & Tan (2010)	Huang et al. (2010)	King (1996)	Mackenzie & Chang (2002)	Perry & McLaren (2004)
Health-Related Quality of Life									
SS associated with concurrent HRQL	Specific functions: 6/6 Overall HRQL: 4/6		[*overall]	✓ Social companionship ✓ Information *Emotional *Tangible *Affectionate	✓SS from family	✓Tangible *Emotional *Appraisal *Information	✓✓	* 2 wks ✓✓ 3mths	✓✓
T1 SS associated with T2 HRQL	1/1							✓	
SN associated with concurrent HRQL	3/3	✓✓ (social activity*/ SN [‡] with specific domains of HRQL only)		✓ size of network for women only ✓ same frequency of contact with children and relatives				* 2 wks ✓ 3mths	
T1 SN associated with T2 HRQL	0/1							*	

✓ significant in univariate analysis; ✓✓ significant in multivariate analysis (DV: depression/depressive symptoms); *no significant relationship
d/c: discharge; SS: Social support; SN: social network; T1: time one; T2: time two; [] results from same study reported in two papers; *HRQL subdomains: Role functioning; General Health; ‡ HRQL subdomains: Change in Health; Environmental mastery