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"I've got somebody there, someone cares": what support is most valued following a stroke?

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Abstract

Purpose: There is often a need for increased support following a stroke. This study explored what types of support are provided by different network members, and what support functions are most valued.

Methods: Adults with first stroke were recruited from a stroke unit, and participated in in-depth interviews 8-15 months post stroke. Framework Analysis was used to build thematic and explanatory accounts of the data.

Results: Twenty-nine participants took part. Main themes to emerge were: the spouse was the most important provider of support; children were a relatively stable source of support, although many participants expressed reservations about worrying a child; relatives and friends typically provided social companionship and emotional support rather than on-going practical support. The only universally valued support function was the sense that someone was concerned and cared. Other valued functions were: social companionship including everyday social 'chit chat'; practical support provided sensitively; and, for many, sharing worries and sensitive encouragement. The manner and context in which support was provided

was important: support was easiest to receive when it communicated concern, and was part of a reciprocal, caring relationship.

Conclusions: As well as measuring supportive acts, researchers and clinicians should consider the manner and context of support.

Key words: stroke; social support; family; friends; aphasia

Running head: What support is most valued post stroke?

Introduction

Stroke is a leading cause of complex adult disability [1], and often necessitates a person receiving additional support, both in managing day-to-day living, and also in coming to terms with unwelcome life changes [2]. Yet receiving support is psychologically complex [3], particularly when the norm of reciprocity is altered by a stroke [4, 5]. The purpose of this study was to analyse the types of support typically provided by different network members (spouse, children, relatives, friends) post stroke; explore how the process of receiving support was experienced; and investigate which support functions were perceived as valuable.

The importance of social contact has long been recognised. In the1960s, Bowlby [6] developed his influential work on attachment and the universal human need to form close, affectionate bonds. Building on this, Baumeister and Leary [7] argued that "the need to belong is a fundamental human motivation." Their belongingness hypothesis was based in evolutionary theory combined with a literature review which found the need to feel meaningfully connected to others was universal across cultures, and that lack of belonging led to physical and psychological difficulties. More recent systematic reviews give credence to this position. A meta-analysis of 148 prospective studies measuring social relationships and illness-related mortality found participants with stronger social networks had a 50% increased likelihood of survival compared with participants with weaker social networks [8]; while another review found quality of relationships was associated with subjective well-being [9].

This close relationship between social support and other outcomes is replicated in the stroke population. A recent review found that depression was significantly associated with low levels of social support in 13/14 studies and reduced social networks in 7/8 studies; and that there was also some evidence (3/3 studies) that social factors, such as receipt of emotional

support or a well-functioning social network, is associated with a person making a better physical recovery following their stroke [2]. The qualitative stroke literature has also consistently found that meaningful relationships are key to living successfully with stroke [4, 10, 11].

The current project sought to explore in more depth participants' experiences of post stroke functional social support (support provided by one person to another) following a stroke. Supportive functions commonly measured include: *emotional support* (feeling loved, valued, understood, confiding concerns or worries); *tangible support* (practical support, such as helping with shopping, finances or personal care); *informational support* (information, advice, guidance); *social companionship* (relaxing, having fun, sharing recreational activities) [12, 13].

While supportive relationships are likely to be key to living well with stroke, the actual process of receiving support has been described as difficult. A meta-ethnographic synthesis of social support post stroke found that receiving needed practical support could lead to distressing shifts in roles within the family, for example, no longer being able to fulfil the parental role, or losing reciprocity within a marriage [2]. In the present project, we aimed to explore which supportive functions were most valued post stroke, and how participants experienced receiving support.

A further aim of the project was to explore whether there were patterns in the support functions provided by different network members (e.g. spouse, children, relatives, friends). The normative expectation in the general population that the spouse provides 'total support' (all support functions) [14], has also been described in the stroke literature [15]. The support functions that can be expected of children and relatives post stroke, however, are less well described. Contact with children has been found to be relatively stable [16]. Children have

been reported to take on practical caring roles following the stroke [17, 18], although there is also variability in the extent to which children are either able or willing to provide tangible support [11]. In terms of relatives, the qualitative stroke literature has found diverse patterns: reduced contact with siblings [19]; siblings interleaving low level support with formal services [17]; relatives rallying around [18]. We sought to investigate the types of support received from both children and relatives, and how this was experienced by participants.

We were also interested in the support that could be expected from friends. Following a stroke people are at risk of losing friends [11, 20, 21]. Yet in the general population contact with friends is associated with higher subjective well-being [9] and friends are likely to share interests and life perspectives potentially boosting self-esteem and identity. Given the difficulties in maintaining friendships post stroke, we aimed to explore the role of friends in providing support, how support from friends was perceived, and what types of support were typically received.

Families of people living with stroke and aphasia are reported to feel excluded from the rehabilitation process, yet it is increasingly recognised that best practice therapy should include important network members [22]. In order that clinicians and services can include network members sensitively within therapy, it may be helpful to have a clear understanding of how different network members typically support the person with stroke, and which support functions are most valued. The specific aims of this study were therefore to explore: whether there are predictable patterns in which support functions are provided by particular network members; how receiving support is perceived; and what support functions are most valued.

Methods

This study was part of a larger project exploring quality of life and social support post stroke [16, 23]. Ethical approval was obtained from the relevant National Health Service (NHS) Local Research Ethics Committees. All those who took part gave informed consent, and names and identifying information have been changed throughout this paper.

Participants

Participants for the larger study were recruited from two acute stroke units based in large teaching hospitals. Eligibility criteria included: being admitted to hospital with first ever stroke; hospital stay of at least three days; over 18 years old. Exclusion criteria comprised: a known history of mental health problems or cognitive decline prior to the stroke; not speaking English pre-morbidly according to self or family report; not living at home prior to the stroke; other severe or terminal co-morbidity, for example, end-stage cancer. Presence of aphasia (language difficulties) was not a reason for exclusion: aphasia presents specific challenges for maintaining social contact [24, 25], so it was considered important that their experiences should be considered within this project.

Participants were followed for six months as part of the larger study, and a subset was invited to take part in in-depth qualitative interviews for the present project at about one year post stroke (range: 8 to 15 months). In order to ensure we selected participants from the larger study in a manner that was systematic and reflected a range of experiences and characteristics, purposive sampling was used [26]. The primary sampling criteria were: stroke severity assessed two weeks post stroke using the National Institute for Health Stroke Scale score [27]; age; and social support assessed six months post stroke using the MOS Social Support Survey [12]. These criteria were used to create a sampling matrix (completed sampling matrix displayed in the results, Table 1). In addition, we monitored a number of

secondary criteria to ensure that they were adequately represented within the overall sample. These included: presence of aphasia, as assessed by the Frenchay Aphasia Screening Test six months post stroke [28]; gender and ethnic background.

Data collection

In-depth interviews took place at the participant's choice of location, which for most was their own home. A topic guide (see on-line supplementary material) was used to guide the interview, covering areas such as their experiences of social support pre and post stroke, how they perceived their social network, and the role of friends and family. Specific questions were not pre-specified in advance, and the order in which topics were covered varied, with interviewer probes following interviewee responses in an organic manner. Interviews took on average 65 minutes (ranging from 38 minutes to two hours six minutes) and were audio recorded. Each participant only took part in one in-depth interview: two participants took a break during the interview, but both elected to continue the interview after a pause.

All interviews were carried out by the first author (SN) who is a speech and language therapist with experience of facilitating people with aphasia. In order to enable people with aphasia to take part in the interviews, a number of measures were taken, such as: the use of total communication (participants were encouraged to use all communication modalities to get across their point), allowing additional time, scaffolding participants' comprehension of topics through writing down key words and using simpler sentence structures. A senior researcher listened to two early interviews and provided feedback, for example, on the questions used and the way topics were introduced. The interviewer also made field notes after each interview, enabling her to reflect, for example, on her own emotional response to the material, as well as information which might not be apparent from the interview transcript (e.g. the physical appearance of their apartment).

Data analysis

All the interviews were transcribed verbatim, and analysed using the Framework method [29]. This method is widely used in qualitative research within healthcare [30]. It offers the researcher a systematic and rigorous method of analysis, enabling them to 'move back and forth between different levels of abstraction' [31], including links back to the raw data, in an iterative process. There are several stages followed in Framework [31]. After becoming familiar with the material, initial themes and concepts were identified, forming the basis of a thematic framework. This was generated inductively, emerging from repeated readings of the data, rather than being pre-specified. The framework consisted of eight main themes (e.g. Theme 2: Family), under which more detailed subthemes were nested (e.g. 2.4 Stroke-related changes to family). This thematic framework was used to 'tag' all the material, thus a decision was made for each phrase or passage as to where it belonged in the thematic index. Thematic matrices were then constructed, with each main theme accorded a separate matrix. Every participant was allocated a row and every subtheme a column. The tagged data was then synthesised and placed in the appropriate cell in the matrices. This matrix-based system facilitated systematic analysis of themes, both within and between participants, from which to develop descriptive and explanatory accounts of the data. All the different stages involved in Framework were carried out through close discussion between the first author and a senior researcher, in order to avoid bias. For example, the senior researcher read a proportion of the charted material in order to consider and discuss the emerging themes.

Results

Participant sampling and characteristics will be presented first. We then present the findings on the support provided by different network members, and also the valued support functions. The main themes to emerge were that the spouse was the primary provider of all support

functions following a stroke, although other network members were important sources of emotional and social companionship support. The only universally valued support function was the sense that others were concerned about them, that they were not on their own. The manner and context of support mattered: support was easiest to receive when it was sensitively provided, and part of a caring relationship.

Participants

Thirty-two participants were selected to take part in in-depth interviews from the 87 participants who took part in the larger study: 29 consented, one declined, and two were no longer contactable. Table 1 displays how the participants fitted in the sampling matrix, while Table 2 presents overall participant characteristics. Of the 29 participants, ten (34%) had aphasia. The majority were white (72%), male (59%) and married/had a partner (55%).

***insert Tables 1 and 2 about here ***

Support provided by different network members (spouse, children, relatives, friends)

Spouse

For all married participants, the spouse was considered the most important source of support. Participants frequently described the central role of their spouse post stroke (*"Husband, wife, that's the most important thing.", Peter*) Participants found it easier to accept help from a spouse than other network members (e.g. friends, children). For example, when Edward was asked if it was easier to receive support from his wife than others, he replied, *"Oh, Good Lord, yes"*. A common attitude was that 'support' was what was expected. Nonetheless, receipt of additional support caused roles to be changed within the marriage, which was often

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a source of distress or anxiety. Following a severe stroke, Tomasz, 68, became reliant on his wife's support post stroke: *"Well, now I am problem for family… [my wife] make sacrifice. She's less happy,"* leaving him feeling *"very depressed."*

Specific support functions: spouse

Emotional support: A main theme was that participants described how their spouse had made them feel loved and valued. The spouse was also the person they were mostly likely to confide in for personal, private or emotional matters. (*"What you discuss with your wife you don't discuss with an outsider,"* Daren).

Social companionship support: Since many participants were spending more time at home, post stroke the spouse was usually the main source of companionship.

Tangible support: The spouse was the only person to provide personal care such as showering or dressing, help with therapy regimes, and give daily reminders to take medication.

Other support functions: Spouses were also conduits for other people's support, passing on messages from the wider community. Finally, being physically close to a spouse gave a sense of reassurance. As Gordon explained, he did not want to go far from home, because *"the wife's here, she knows what to do"*.

Case example: spouse as main provider of support

Pablo was 55 when he had a severe stroke. One year post stroke he still had moderate expressive aphasia, could not drive, and had impaired mobility. He lived with his wife and two sons. Although he said his relatives and sons were *"very good"*, and he had some close friends, it was *"My wife, number one. I got to shower, I got thing like that,*

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everything from, for me." It was also his wife he talked to about personal things, or about his private worries. And it was his wife who visited him every day for three months when he was in hospital.

Children

Children did not provide 'total support', like a spouse. It was common for participants to express conflicted feelings about accepting support and 'worrying' a child or being a burden. Accepting help, rather than providing help, was a difficult shift. As Edward explained: *"It's me who should be looking after them, you know, it's this parental thing."* However, where a spouse was not available, participants generally preferred to ask their child for help rather than a friend or relative.

Children were mostly a robust source of support. Even those who had lost touch with almost everyone in their social network tended to remain in contact with their children.

> **Case example: Dolores and the squirrels**
> Dolores was 66 and divorced when she had a stroke which left her with aphasia, severe physical disablties and needing nursing home care. Thirteen months later, she had lost touch with all her friends and work colleagues *("bad friends I call them because now, since I got here, no-one came in to see me")*. Her relatives did not live locally, and would visit around once a month. She had one child who worked long hours in a shop, and had to catch two buses to reach the nursing home. Still, her daughter made this trip twice a week, and would take her mother out to the local park to feed the squirrels *("So we sit there. It's nice… Oh, I enjoy to tell you the truth")*.

There was variation in the levels and perceived adequacy of support received from children, however. A subset received what they perceived as inadequate support. These participants described troubled relationships with the child prior to the stroke. Having a stroke created

expectations and hopes of what might be expected from a child, and when these were not met, it was a cause of distress. Other reasons for a child providing limited support were: a child living far away; the child's ill health; and the child having other family commitments, work commitments or time consuming hobbies. In some cases, children succeeded in communicating a real sense of concern despite limited face to face contact, through telephone calls, thoughtful tokens such as cards or small gifts, and hospital visits. Rose, reflecting on the support received from her daughter, said: *"Somebody can be supportive if they're one hundred miles away… I've always felt my family were supportive, whatever distance they were."*

Specific support functions: children

Emotional support: Feeling a child was concerned or cared was highly valued post stroke when many participants were feeling vulnerable and low. Susan described how her daughter, who lived the other side of the country, dropped other commitments to come to the hospital and stay in London for a short while, which was "*a dream"*.

However, participants mostly did not confide in their children about a private worry. A common reason was that they did not want to worry their child, or impose on them, or make the child feel obligated. Frequently expressed was the sense that the child had their own life to lead, their own families to look after, and their own worries or health problems. The subset who did confide in their children described mixed feelings. There was no-one in this project whose sole confidante was a child.

Social companionship support: Many participants spoke about being taken out by their children following their stroke, for example, to a café, park, shops or cinema. As grown up children were likely to be fitter and more able than an elderly spouse, they were often better placed to take the individual out. Since a subset of participants were either unable or reluctant

to leave their house on their own, this sort of support could take on a different significance from prior to the stroke, when they had been more independent and socially active.

> **Case example: the psychological boost provided by being taken out**
> Daren was 65 and prior to the stroke was working and active. Ten months post stroke he was still unable to walk outside the house. His lack of mobility had made him despair at times. However, his family were *"very, very close"*, and meant *"everything"* to him. He described the impact of his son taking him for a drive: *"Just to give me some fresh air instead of staying in the house… Make you happy, brings some life back. Life, breath, strength. When they come, see, it wakes you up, make you feel that you are wanted, you feel depressed before, you just forget it."*

Tangible support: Children helped buy small items, took letters to the post office, helped to fill out forms or gave lifts. Unlike friends or relatives, it was not uncommon for children to help on a regular basis with tasks such as food shopping. Children also acted as advocates for their parents, for example, talking to medical personnel. However, no child in this study provided personal care other than one child who helped his father shave. In situations where there was no spouse, or the spouse was disabled, personal care was provided by paid carers. Nor did any child help with physical therapy or remind participants to take medication. This was equally as true for participants who lived with their children as those who did not.

Relatives

The most common narrative was that the stroke had made people closer to their relatives. Commonly described was how relatives had *"drawn closer", "rallied round"*, been in more frequent contact. In one instance, the stroke was a catalyst for the resolution of a family dispute. However, the stroke was also a reason for participants to receive less support from relatives. Firstly, relatives, unlike children, were more likely to have health problems of their own, since they were often the same age (e.g. siblings, cousins) or older (e.g. aunts) than the

participant. For a subset of participants, prior to the stroke they had been the healthier one, visiting the relative, which was no longer possible post stroke. A further reason was that aphasia made telephone contact with relatives living abroad more difficult. An example is Leonisa, who spoke regularly to relatives living in the USA and Indonesia prior to the stroke. Post stroke she *"have to repeat and repeat because I always mistakes,"* meaning that she spoke to them *"not too much"* since the stroke.

There was wide variation in how much support was provided by relatives. For a subset, a sibling was a primary source of support. Others described supportive face-to-face contact with one or two relatives who often lived nearby. Nieces and nephews were more likely to take on a supportive role for those who didn't have children. Several participants spoke of great networks of relatives, providing collective support. Support, however, was rarely expected from relatives.

Specific support functions: relatives

Emotional support: Phone calls, visits, cards, small gifts such as tapes of music, made participants feel that that the relative was thinking of them and cared about them. In terms of confidantes, participants would typically confide in a spouse rather than a relative. However, single female participants all had confiding relationships with relatives, mostly a sister, but also aunts and cousins.

Relatives' concern: helping recovery after a stroke

Raymond, aged 66, had a severe stroke. His brother, who lived in America, phoned him at least once a week since the stroke. He also sent him a weekly newspaper from the West Indies, where they grew up, to cheer him up. This level of concern and

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> thoughtfulness made him feel *"good, good, yes, very good...it take some of the stress off you."*

Social companionship: Many participants described how seeing their relatives cheered them up, made them laugh and relax. Given that often their social horizons had been limited by the stroke, this contact could take on a more central role in some of the participants' lives, as illustrated by Martin. Before his stroke, he used to see his friends at the betting shop or out and about on his daily walks. Following the stroke, he rarely left his flat. The only person he saw regularly apart from his children was his sister-in-law, who lived in the same block of flats, and whom he met twice a week. When asked why this contact was important to him post stroke, he replied simply, *"I haven't many friends."*

Tangible support: In this study, relatives did not provide personal care, liaise with medical staff or other professionals, or help the participant to comply with any medical or therapy regime. Further, it was unusual for a relative to help with housework, or to go shopping for them. As John explained, *"I don't expect them (relations) to be around when I need shopping."* The exceptions to this were two unmarried elderly women in the project who received practical help from relatives. However, this was a vulnerable source of support in both cases: in one case, the relatives lived abroad, and only came over occasionally; in the other case, the elderly sister was herself admitted to hospital, and could no longer help the participant.

Friends

As described elsewhere [32], contact with friends typically reduced post stroke. For many, family, rather than friends, were the primary source of functional support post stroke. For example, Peter, 65, felt you couldn't expect to receive any support from friends: *"There's*

nobody else going to do anything for you, other than members of your family, nobody... you can't expect friends to do things, you know." Nonetheless, for many participants, friends were an important source of some types of functional support.

Specific support functions: friends

Emotional support: When asked what made someone a good friend post stroke participants described how a good friend cared about them, was concerned, thought about them. Following a stroke, people wanted their friends to be in touch, to find out how they were. Friends were also a valuable source of confiding emotional support for some participants. This is illustrated by Patricia whose main confidante was a friend. She rarely confided in her children, and had not told her new partner that she'd had a stroke. However, she derived much support from almost daily emails written to an old friend who lived abroad. She described what she gained from this contact:

> *"Back up. It's a back up to things that I think myself….I found it a tremendous comfort. There were times when I was absolutely despairing, I didn't know what to do with myself…But I would go in to sit on the computer [to email her friend], and that gave me a sort of soundness."*

Confiding emotional support, however, was not a form of support that was universally either experienced or necessarily wanted from friends. Some preferred less emotionally laden conversations. There was also the worry about burdening friends, particularly if emotional distress persisted long term. For example, Pratik did not confide in friends, and could not imagine doing so. For him, to confide in even his closest friends *"would be just weird, awkward for the both of us."* Instead, he wanted to *"just talk to them about normal stuff, like a friendship should be, because you don't want to destroy that friendship, you don't want to burden them with more responsibilities about how you're feeling."* Other participants said

that they wouldn't feel it was right to confide in friends about private matters, particularly those relating to the family.

Social companionship: Many participants spoke of how much they enjoyed chatting, joking, relaxing and having fun with friends. Participants would describe such conversations as having a *"right old chinwag"*, or *"a good old natter."* Given the newly restricted lifestyle of many participants, and the depression that often accompanied this, the value of friends coming over and making them laugh could be great. Bridget, for example, stated that the thing that helped her recover from post stroke depression was *"just a friend coming and having a laugh and a joke."*

Case example: the value of every day chats with a friend

Dorothy was 86, living alone, and rarely saw her friends due to poor mobility. She described what she gained from regular telephone conversations with her old friend Nancy: *"What they've been doing, and what I've been doing, and what I've not been doing. [laugh]. Nancy and I generally explain all our aches and pains…. it's nice to speak to somebody, somebody you know and like, and you can imagine, yes. Especially if I haven't spoken to anybody, you know, all day, and then I have a phone call, it's rather nice, you know, just have a chat."*

Many participants who lived with family members also described the particular value of a friend visiting them. The less mobile participants described sitting all day long with their partner, talking about the same things, watching the same television. A visit from a friend could cheer them up, make them feel more positive, take their mind off their problems. As Susan said of a neighbour who called in and chatted to her: *"You feel better, you feel better… Gives you an uplift, if you might say."*

Tangible support: Friends commonly bought small inexpensive and non-essential items, typically a newspaper or food such as cake or fruit. Several participants also described how they would let friends and neighbours help them with small practical matters, such as taking the top off the bleach. Being able to count on local friends and neighbours in the event of an emergency, for example, a second stroke, was also commonly described.

It was unusual to receive substantial tangible support from friends, however. Where it was given it would typically be time-limited, which contrasts with the on-going nature of tangible support provided by family. There was no-one who reported receiving personal care from a friend. Moreover, there was a reluctance to ask friends for practical help, especially if the help they needed was perceived as time consuming, expensive or burdensome. An example is Gerta, aged 82 and living alone. She described how difficult she would find it to go clothes shopping on her own after the stroke. Over a year post stroke she had preferred not to buy clothes rather than impose on friends. She had no family to help.

> *Gerta: I want to go in weeks and weeks to John Lewis to buy [clothes and shoes], I have avoided it, thinking of busy Oxford Street and so on…but I mean I can find somebody, to say, have you got time [to accompany me]. It's a question of asking sometimes.*

> *SN: And are there people that you feel you can ask?*

> *Gerta: Yes, about two or three I think I could ask, yes. But I always think of their life, how much time they can spare.*

Not only was asking for help perceived as difficult, participants also reported turning down offers of help. Reasons included wanting to feel independent, not wanting to feel obligated, and not believing that the offers were really meant. Worries about not being able to reciprocate also made participants less likely to accept offers of help. This is articulated by Peter. No longer able to drive post stroke, friends had offered to give him lifts, or come to

him, which he had declined. He gave the following rationalisation: *"You've got to, it's a two way street, isn't it? You want to see, you can't expect people to come all the time."*

What support functions are most valued post stroke?

Emotional support

Feeling that someone cares and is concerned: The sense of needing to feel connected to someone who cared and was concerned appeared to be universal post stroke. When asked what had helped most after their stroke, participants typically alluded to this (*"I'd have to go back to concern… my constant word, concern, yes,"* John; *"It's knowing that someone cares about you,"* Ivy)

The importance of this type of support following a stroke is demonstrated by those who did not feel they received it. Patricia, who was 62 when she had the stroke, described how her daughter did not visit her in hospital, and never asked how she was. As Patricia struggled with feeling unwell, suddenly 'old' and vulnerable, she wanted to feel connected to her daughter: *"The one thing that I needed, the only thing I needed from her, was a little bit of concern now and again, and I haven't had that."* When asked how her daughter could have given her this sense of concern, she replied, "*Just a telephone call now and again would have been the most important thing, yes."* The impact on her relationship with her daughter was that she was, "*furious, very hurt".*

Linked to this sense of concern were other constructs. Participants described wanting to feel accepted as they were post stroke, feel that someone knew them well and understood what the stroke meant to them, and that others would be patient and tolerant as they adjusted to post-stroke life.

Confiding emotional support: Having at least one person to confide in and talk about the emotional impact of the stroke was valued by many, although not all, participants. They appreciated being able to say how they really felt, express worries and negative feelings. Dolores explained that due to the stroke she "*was bitter inside there. I was really mad.*" Being able to talk, and cry, with her sister helped: "*you see, I was building everything in, but after that, when I cry, I said the thing what I have, I feel much better.*"

Sensitive encouragement: Encouragement was also described as helpful by some when recovering from a stroke. Participants described how a supporter would give them "*encouragement*", "*confidence*", "*courage*", "*strength*" or "*hope*". Winnifred described how her husband had '*healed her*' after her stroke. "*If you don't have anybody giving the encouragement, you cannot go on, because you say, oh no, no, no , no, no… it is the strength of my husband that make me pull through life as I am now, because if he's strong, I am strong.*" However, encouragement to do things the participant did not feel ready for could make them feel the other person was not aware of what they were going through. Being told to 'keep your spirits up' also engendered mixed feelings. Thus encouragement was arguably most valuable when provided sensitively.

Social companionship

Every day social 'chit chat' could lift a person's mood, and make a person feel connected to others. For some, joking and laughing was considered the most valuable support another could give. When Paul was asked how people had helped him after the stroke, he stated simply: "*Being able to joke*".

 'Responsive' tangible support

Receiving additional tangible support post stroke was not perceived to be easy. As observed by Cormac, tangible support that was provided insensitively could have negative

psychological consequences: he described how "*overdoing*" the help made him "*feel an invalid… absolutely worthless*'" One way of mitigating these psychological costs was when tangible support was perceived as 'responsive' (defined as support that makes the recipient feel loved and esteemed [33]). An example is Dorothy. Dorothy was 86, lived alone and had one daughter. Her daughter was the primary provider of all support, including tangible support.

> *"She does little helpful things. She knew, this is just an example, she knew I wanted a new ironing board, but there was nothing really the matter with the actual board, it was the stuff, you know, under the board, broken away. I'd made new covers. And she went to one of these big do it yourself places I think, and you could buy, like, a new piece to put on, about that thick."*

The fact that her daughter had not only noticed her mother's ironing board, but had the sensitivity to buy new 'stuff' rather than a complete new board, so as not to waste her mother's newly made covers, is arguably an example of responsive tangible support. Dorothy commented her daughter was *"so concerned about me"* and described how happy and grateful she was to have such a daughter.

More generally, the provision of tangible support often appeared to be primarily appreciated for the extent to which it communicated care and concern, thus arguably overlapping with 'emotional support' function. For example, the gift of a small radio when in hospital was appreciated because it made the recipient feel his daughter cared, that even in hospital he wasn't really on his own. Conversely, some intensive tangible support (for example, cooking someone their meals every day) did not necessarily lead to a sense that the other person cared about them, which could leave the participant feeling isolated and detached from their supporters.

Informational support (contingent on level of knowledge of supporter)

Participants spoke about wanting informational support delivered by an informed healthcare professional. However, advice and information could be irritating if given by someone who they felt didn't understand or had only limited knowledge. For example, Pratik described relatives who *"don't have knowledge"* about strokes, and told him to *"rub chicken blood on my hand."* Participants also described disliking being over-advised and *"fussed"* post stroke by relatives or friends. On occasion the informal support network did provide information of value, such as a friend advising them they were eligible to apply for free gym membership, or a family member having particular expertise (e.g. a nephew who was a physiotherapist). However, participants did not mention Informational support when describing what they most valued from a friend or relative.

Manner, context and purpose of functional social support

As observed above, receiving functional support was often challenging. Support appeared easiest to receive if it was reciprocal, 'responsive', and part of a caring relationship, suggesting that context and manner of providing support matter. An example of someone describing reciprocity and sensitivity of support is Edward. He described how he and his wife *"help each other as we can"*, as he recovered from his stroke, and his wife from chemotherapy. In addition to the practical support and encouragement (e.g. to resume activities), he described how he values sharing concerns and confiding his worries (*"even if it's a silly thing, sometimes, just need to say it,"*), and the sensitive way she has responded to his needs, for example, reading aloud to him more since the stroke (*"[my wife] reads poems very well you see, I love poems being read to me."*)

Finally, functional social support was valued partly for mediating other outcomes post stroke such as reducing stress levels and alleviating depression (as described above in Daren's and

Raymond's case examples), but also for something more fundamental: whether a person felt connected or on their own. This is illustrated by Gordon. When asked about the support received from his family, he explained why it was important: *"I've got somebody there, someone cares… That's the main thing, the best thing, knowing that they're there… I'm not on my own."*

Discussion

We interviewed 29 people about one year post stroke and explored the role of social support. There were predictable patterns in the types of support provided by different network members, with the spouse typically providing 'total' support. Children and relatives were a valued source of companionship and concern, although it was common for participants to feel conflicted about receiving support from a child. Despite the overall reduction in contact with friends, for many participants friends were still a source of humour, enjoyable distraction, and emotional support. Valued support functions included: feeling others were concerned and cared, social companionship, tangible support provided sensitively. For many post stroke, the manner and context in which support was provided was important: support was easier to receive if it communicated concern and was part of a caring relationship.

In line with the normative expectations described by Wenger [14], the spouse was the primary provider of all types of functional support, replicating previous stroke research [2]. Also in line with Wenger [14], relatives primarily provided social companionship and emotional support. However, the stroke meant that these familial sources of companionship support took on more significance, as the person's non-kin contact tended to reduce e.g. through lost work, lost social activities, reduced contact with friends [32].

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The support most valued from children post stroke was concern. The main factor determining who received this appeared to be the quality of the relationship prior to the stroke. Other research has found that how adult children support their elderly parents can be predicted by patterns set up earlier in life: early family environment has been found to affect frequency of contact [34]; and those who receive more help tend to have invested more in their children [35]. Where the quality of the relationship with their child was high, participants could still feel close and perceive themselves to be well supported despite limited face to face contact. The Pinquart and Sorensen [9] review also found that it is quality rather than quantity of contact with children that is most strongly associated with subjective well-being. Another support function that participants valued from children post stroke was social companionship. This contrasts with the ambivalence expressed on receiving substantial tangible support. In the general population, receiving tangible support from a child is associated with depression even when measures of need (e.g. health status) are controlled for [36]. For many participants, receiving significant tangible support conflicted with their desire to maintain the parental role if at all possible; for similar reasons, most participants felt conflicted about confiding private worries to a child.

In the general population, contact with friends has been found to be important for psychological well-being [9]; and for an older person, having a well-established friendship network is associated with enhanced survival [37]. The particular role of friends in providing humour, distraction and companionship was described in both the current data set, and previous research exploring the lived experience of aphasia [10, 21]. No participants in the present project, however, received substantial ongoing tangible support from a friend. Some participants explicitly referred to their inability to reciprocate such support post stroke: reciprocity has been argued to be an important dynamic in a friendship [38], which may explain participants' reluctance to feel indebted to a friend.

A main finding in the present study was that support was often challenging to receive following a stroke, and that its perceived value rested on the *manner* and *context* of the supportive act. In terms of the manner in which support was provided, a strong theme was that support was most valued when it communicated concern. Other stroke research has also highlighted the difficulty of being in receipt of support, and documented the sensitivity needed to provide practical support while enabling a person to maintain their self-esteem and self-efficacy [4]. There is some evidence that the psychological cost associated with receiving practical support in the general population is mitigated when the support is perceived as 'responsive', defined as support which makes the recipient feel understood, valued and cared for [33]. An alternative way of conceptualising this finding is that tangible support is most valued when it overlaps with emotional support. Conversely, there is evidence that apparently supportive acts can be perceived as unhelpful and unwelcome, carrying a psychological cost. In the present project participants described the distress associated with 'overdone' tangible support, and advice was often considered irritating. A stroke study found that unwanted advice about how the person should change their way of doing an everyday activity was the most frequent negative interaction post stroke, followed by unwanted assistance with basic activities of daily living: negative interactions explained more of the variance in physical recovery and personal adjustment from stroke than positive social interactions [39].

Context was also important: support received within a supportive, caring and reciprocal relationship was easier to receive. The desire to fulfil valued social roles and to contribute post stroke is well-documented [40]. In a project exploring what is important to people with aphasia, the authors noted that 'interestingly, their goals included wanting to help others.' (p309) [41]. It may be that in situations when reciprocity is no longer possible, then the manner of support becomes particularly important, which may explain why support provided with concern was so highly valued post stroke in the present project.

These findings have implications for how social support is measured post stroke. Outcome measures which focus on discrete support functions may not adequately capture either manner or context of support, nor the overlapping nature of some functions, nor the potential psychological cost of receiving unreciprocated or unwelcome support. Further, outcome measures that assume a person values all types of support are potentially problematic: in the present project not everyone valued all the commonly measured support functions. For example, not everyone wanted to confide their private worries or receive advice.

The mechanisms through which social support impacts on other outcomes is debated: receipt of support has been found to reduce stress levels, and can influence a person's self-esteem, self-efficacy and decision to self-care, indirectly impacting on physical health [3]. However, there is also some evidence that social support can *directly* affect physiological functioning, even after controlling for stress or other psychological factors [42]. In the present project, participants explored the stress-relieving aspects of support (e.g. social companionship), and described how it gave them a psychological boost. However, knowing someone was concerned about them, that they were not alone, appeared to be highly valuable in itself, and is perhaps suggestive of this direct effect. After an illness, it may be a fundamental human need to feel connected in some way to others, and that, as suggested by Bowlby [6], this is a "primary motivational system".

Strengths and limitations

Strengths of the study were the robust sampling procedure, providing reassurance that a diverse range of experiences were captured, including the experiences of people living with aphasia. Nonetheless, only two participants were aged under 50, and only one participant was living in a nursing home. Of the thirteen married participants, ten were male. This may have influenced findings: for example, the tendency for married participants to confide in their

spouses rather than friends. Further, spouses were present in some interviews, potentially making it more awkward for participants to discuss their role post stroke. Finally, different patterns may have emerged had the interviews been conducted in the longer term post stroke: it may be that at one year post stroke, some post stroke support patterns were still evolving. In terms of the generalisability of the results, this sample was recruited from one inner city UK stroke unit, and may not be transferable to other sociocultural contexts. For example, in countries with less well-developed formal care systems, children may be more likely to provide intensive tangible support post stroke. In terms of trustworthiness of the analysis, although the primary analysis was conducted by the first author (SN), it is reassuring that a senior researcher acted as a second analyst at key stages in the analytic process.

Future directions and implications

In terms of clinical implications, the spouse was the key provider of functional support. Yet the stress and exhaustion experienced by carers post stroke is well-documented [15]. In order to enable carers to provide ongoing 'responsive' tangible support, the psychosocial well-being of the carer and suitable carer support options should be promoted within stroke services. Further, given the key role of carers, rehabilitation is likely to be most successful if carers are sensitively included in the process [22].

This project found that while family provide many supportive functions, nonetheless, friends often play a valuable role post stroke, for example, in provision of social companionship. Given the vulnerable nature of friendships post stroke [11, 32], rehabilitation that targets sustaining friendships, as well as opportunities for peer support between people with stroke, may be valuable.

The current project suggests that the sense of feeling connected to others was of central importance to people living with stroke, thus researchers and clinicians should seek sensitive

ways to measure this construct. Potentially, measures of perceived social isolation, such as the Friendship Scale [43], may indirectly capture this. It is also likely that measures that assess *perceived* functional social support (i.e. the subjective experience of perceiving oneself to be supported), may more closely measure this sense of feeling others are concerned, than measures of *received* support (i.e. observable 'enacted' support). Future measures should consider further how best to measure the context (e.g. contribution, reciprocity, quality of relationship) and manner (e.g. responsiveness, sensitivity) of support, as well as the value of everyday companionship, following a stroke.

Conclusion

Twenty-nine participants took part in in-depth interviews at approximately one year post stroke exploring social support. The spouse was the main source of all support functions, but participants also valued the concern, companionship and emotional support provided by children, relatives and friends. Nonetheless, wanting to maintain the parental role sometimes meant they felt conflicted about receiving support from a child. Valued support functions included social companionship (humour, being taken out, social 'chit chat'), practical support that communicated concern, encouragement, and confiding emotional support. The only support function that was universally valued by all participants was a sense that others were concerned about them, and that they were not alone. Researchers and clinicians should consider the manner and context in which social support is provided post stroke: support was most valued when it communicated concern, and was part of a reciprocal, caring relationship.

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Declarations of Interest

The authors report no declarations of interest.

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Table 1. Distribution of participants in the sampling matrix

	Moderate-Severe stroke (NIHSS 11+)		Moderate stroke (NIHSS 6-10)		Mild stroke (NIHSS 0-5)	
	≤ 65 years old	66+ years old	≤ 65 years old	66+ years old	≤ 65 years old	66+ years old
Good social support*	Raymond; ♂; 63 yrs; spouse; **(aphasia)** Edward; ♂; 58 yrs; spouse; f/t work	Ivy; ♀; 82 yrs; alone	Winnifred; ♀; 65 yrs; spouse	Gordon; ♂; 74 yrs; spouse	Brian; ♂; 57 yrs; spouse; p/t work	Judy; ♀; 76 yrs; alone Cormac; ♂; 75 yrs; Spouse
Moderate social support*	Peter, ♂; 65 yrs; spouse Pablo; ♂; 65 yrs; **(aphasia)**; Family	Adebomi; ♀; 68 yrs; **(aphasia)** alone Tomasz; ♂; 66 yrs; family	(n = 0)	Paul; ♂; 76 yrs; alone	Daren; ♂; 65 yrs; spouse	Dorothy; ♀; 86 yrs; alone Andy; ♂; 69 yrs; **(aphasia)**; spouse John; ♂; 76 yrs; alone Rose; ♀; 90 yrs; spouse
Poor social support*	Chris; ♂; 58 yrs; **(aphasia);**alone Steve; ♂; 48 yrs; **(aphasia);** alone Hakim; ♂; 63 yrs; **(aphasia);** spouse	Dolores; ♀: 66 yrs; **(aphasia)** nursing home	Pratik; ♂; 18 yrs; family; f/t education	Leonisa; ♀; 74 yrs; **(aphasia);** alone Bridget; ♀; 74 yrs; alone Susan; ♀; 78 yrs; spouse	Patricia; ♀; 62 yrs; **(aphasia)** child	Gerta; ♀; 83 yrs; alone Martin; ♂; 68 yrs; child

Explanatory note: ***Social support** measured by the MOS Social Support Survey six months post stroke: participants grouped according to whether they scored in the top, middle, or bottom third of the population;

NIHSS: National Institute for Health Stroke Scale.

aphasia: indicates aphasia post stroke; Alone/ family/ spouse/ child: indicates who the participant lives with (where family implies spouse and child); employment status: not working unless otherwise specified. Yrs: years.

Note: all names have been changed

Table 2. Participant characteristics (n=29)

Characteristics		Participant numbers
Gender	Female	12
	Male	17
Age	Mean (S.D.): 68 years old (14 years); Range: 18 to 90	
Ethnic Group	Asian	2
	Black	6
	White	21
Co-morbidities	None	3
	One	8
	Two	4
	Three or more	14
Marital status	Married or has partner	16
	Single, divorced, or widowed	13
Children	Has children	21
	Does not have children	8
Stroke Type	Ischaemic	21
	Haemorrhagic	8
Mobility	Walks independently, no limitations	9
	Walks independently, with limitations (e.g. reduced stamina, unsteadiness)	9
	Walks with assistance	5
	Non-ambulant	6
Communication disability	Aphasia	10
	Dysarthria	1
	None	8