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Why do people lose their friends after a stroke?

Abstract

Background: It is well-known that people lose friends after a stroke; what is less well understood is why this occurs.

Aims: This study explored why people lose contact with their friends, and whether there are any protective factors. It also examined how friendship loss and change is perceived by the individual.

Methods and Procedures: Participants with a first stroke were recruited from one acute stroke unit in the UK. In-depth qualitative interviews took place between 8 and 15 months post stroke.

Outcomes and Results: 29 participants were recruited of whom 10 had aphasia. The main reasons given for losing friends were: loss of shared activities, reduced energy levels, physical disability, aphasia, unhelpful responses of others, environmental barriers, and changing social desires. The subset of participants who experienced the most extensive loss of friends were those who described a sense that they were 'closing in' on themselves leading to a withdrawal from social contact and a new preference for meeting only close friends and family. Those with aphasia experienced the most hurtful negative responses from others and found it more difficult to retain their friends unless they had strong supportive friendship patterns prior to the stroke. The factors which helped to protect friendships included: having a shared history, friends who showed concern, who lived locally, where the friendship was not activity-based, and where the participant had a 'friends-based' social network prior to the stroke.

Conclusions and Implications: Given the link between depression and loss of friends post stroke, supporting an individual in maintaining a social network is likely to be beneficial. For

intervention to be effective, however, it may need to take into account not only the impact of new physical and language disabilities, but also changing social desires.

Introduction

It is well established that people are at risk of losing their friends after a stroke (Astrom *et al.* 1992). This situation is particularly well-documented for those who have aphasia (Cruice *et al.* 2006, Davidson *et al.* 2008). For example, in a study of 83 people with chronic aphasia, 64% reported that they saw their friends less than before the stroke, and 30% reported having no close friends at all (Hilari and Northcott 2006).

For those who do lose touch with friends, they appear to be at higher risk of depression, particularly in the longer term after a stroke. In a three year study of 80 patients, the most important predictor for depression from 12 months onwards was the patient's having few social contacts outside the immediate family (Astrom *et al.* 1993). Other studies have found that loneliness (Hilari *et al.* 2010), social isolation (Appelros and Viitanen 2004), and failure to resume social activities (Angeleri *et al.* 1993) are all associated with depression in the chronic period post stroke.

More generally, in the elderly population there are benefits for those who have diverse social networks rich in friends. Large scale studies in Israel (Litwin 2001) and the US (Fiori *et al.* 2006) have shown that those who have 'diverse' or 'friends-based' social networks have higher morale than those in restrictive or family-based networks. A meta-analysis conducted by Pinquart and Sorensen (2000) also suggests that contact with friends is associated with higher subjective well-being. Further, there is evidence that having a well-established friendship network may enhance survival in the elderly (Giles *et al.* 2005).

In considering why friendships may be so important in later life, various reasons have been put forward. One is the sense of continuity that friends may provide: a friend typically

belongs to the same age group, and thus is likely to have shared history and life perspectives, which may help bolster identity. There is also the sense that people choose their friends, and that friendships are usually reciprocal and based on shared values, interests and activities (Hartup and Stevens 1999). This in turn has been argued to be a boost to self-esteem (Lee and Shehan 1989), and may increase feelings of usefulness (Jerrome 1991). Additionally, friends can be an important source of out-of-house socialising and having fun which can increase subjective well-being (Larson *et al.* 1986).

Thus there are clear benefits in maintaining contact with friends. The prevalence of friendship loss post stroke is therefore a cause for concern. However, although friendship loss has been well documented, much less is known about *why* people lose their friends, nor is it well understood how this process is perceived by the individual. Further, not everyone loses their friends, and even those who do are unlikely to lose all of their friends. Yet it remains uncertain which factors protect some friendships and not others, and which people are particularly at risk of losing their friends. A clearer understanding of these issues, however, may enable clinicians and service providers to more effectively support the friendship networks of those who have had a stroke. In order to unravel the processes by which friendships are lost after a stroke, a qualitative approach was used: qualitative methodology can be useful in seeking explanations about why and how a phenomenon is occurring (Ritchie 2003). It is also a methodology that has been successfully used with those with aphasia: the flexibility of the format means that people who might have difficulty responding to the language demands of survey questionnaires can be enabled to describe their concerns and experiences (Parr *et al.* 1997).

Friendship has been variously defined in different contexts and projects. The term ‘friend’ in this research covers all social contacts who are neither family nor paid, including both close, confiding friendships as well as those more peripheral to the individual. This paper addresses the following research questions:

1. What are the perceived causes of friendship loss after a stroke?
2. What factors help to protect friendships?
3. How is friendship loss and change perceived by the individual?

Methods

This study was part of a larger study looking at the assessment of quality of life post stroke (Hilari *et al.* 2009). Participants for this larger study were recruited from two acute stroke units based in teaching hospitals, and were followed for 6 months. Participants were invited to take part in the initial study if they were over 18 and admitted to hospital with first ever stroke. They were excluded if they had other severe co-morbidity; were too unwell to give informed consent; were not living at home prior to stroke; had a known history of mental health problems or cognitive decline; or did not speak English pre-morbidly. For the present study, a subset of these participants was selected for in-depth qualitative interviews which took place about a year post stroke (8-15 months).

The study was approved by the relevant National Health Service (NHS) Local Research Ethics Committees. All those who agreed to take part in the study gave informed consent. Where appropriate, the researcher gave information on local support services, social activities and other information sheets to participants following the interview. All names and identifying details have been changed throughout this paper.

Sampling procedure

Purposive sampling was used to optimise the diversity and range of characteristics that were of relevance, such as large or small friendship networks (Ritchie, Lewis and Elam, 2003).

Deciding who to interview was determined by pre-set selection criteria to ensure that selection was systematic, and captured the different experiences. The following criteria were used:

- **Severity of stroke:** this was assessed two weeks post stroke using the National Institute for Health Stroke Scale score (NIHSS) (Brott *et al.* 1989).
- **Age:** the two main categories were over 65, i.e. likely to be retired, and 65 and under
- **Social support factors** (using data collected 6 months post stroke): these included number of close friends; total size of network; whether living alone; marital status; perceived social support using scores from the Medical Outcomes Studies Social Support Survey (SSS) (Sherbourne and Stewart 1991), which was adapted in presentation to be accessible to people with aphasia (see Hilari *et al.* 2010).
- **Aphasia:** participants were defined as having aphasia from their Frenchay Aphasia Screening Test (FAST) scores at 6 months (Enderby *et al.* 1987). There was one exception: a participant who scored in the 'normal' range, but where both clinical judgement and participant perception indicated the presence of aphasia.
- **Gender and ethnic background:** these variables were monitored to ensure the choice of participants mirrored the larger stroke population from which participants were being drawn.

All participants recruited from Site One of the larger study, where the first author was based, were eligible to be considered for this study. Since those with aphasia are reported to face

particular social challenges they were preferentially included so that their experiences could be compared with those without aphasia.

Participants recruited

32 participants were selected to take part: 29 consented, two were no longer contactable, and one declined. Participants ranged in age from 18 to 90 years old, 12 were ≤ 65 and 13 were working prior to the stroke; 12 participants were women; and roughly half (15) were white British. Stroke severity (NIHSS) scores ranged from two (mild) to 21 (severe), mean (S.D.) 9 (5.5). In terms of social factors, they ranged from having no friends to having 20 close friends; 17 lived with family members, nine lived alone, two lived in sheltered housing and one lived in a nursing home; 14 were married; and 21 had grown up children. 10 participants had aphasia. In terms of their FAST scores at two weeks post stroke seven had severe expressive aphasia (expression scores on the FAST 0-3 out of 10), of which two also had severe receptive aphasia (auditory comprehension scores on the FAST 0-3 out of 10). By the time of the qualitative interview, clinical judgement indicated two participants persisted with severe expressive aphasia, and a further five participants had moderate expressive aphasia of which two also had mild receptive aphasia. Figure One shows how the participants fit into the sampling matrix, while Table One gives further information on participant characteristics.

insert Figure One and Table One about here

Data collection

A topic guide was used, covering areas such as friendship patterns pre and post stroke, the role of friends in adjusting to the stroke, as well as discussion of social support more

generally. The guide did not include specific questions, but flagged up points to be explored. The order in which topics were discussed varied from participant to participant, following in an organic way from participant responses. Interviews took on average 65 minutes (ranging from 38 minutes to two hours six minutes), and were audio tape-recorded, with the permission of the interviewee. Participants chose the venue for the interview, usually their home. All participants elected to conduct the interview in one sitting. Field notes were made shortly after each interview, allowing the researcher to reflect on how the interview had gone, for example, how topics had been presented, and making note of anything that would not be on the audio-tape, such as the mood of the participant pre-interview.

The interviews were carried out by the first author, a speech and language therapist with experience of working with those who have had a stroke and aphasia, and trained in qualitative interviewing techniques. Two early interviews were listened to by a senior researcher, who gave feedback helping to ensure that the interviews were non-biased and open-ended.

The following measures were used to assist people with aphasia during the interview. Firstly, the interviewer took care to modify her own language, and use and be responsive to any communication modality favoured by the participants, including writing, gesture, the use of objects in their home environment and communication aids such as a communication passport. The interviewer also verbally commented on the participants' non-verbal gestures as they occurred, which helped to ensure their meaning was correctly understood, and also meant there was a verbal record on the audiotape to be analysed later. Finally, where a participant had aphasia the interviewer brought along a booklet with the topics laid out in an aphasia-friendly manner (for example, key words emboldened, use of white space). This book was

used flexibly, thus preserving the ability to cover topics as they came up, while still giving a level of ‘scaffolding’ to the interaction to aid comprehension.

Two excerpts from interviews are available in the online version of the journal (Appendix One).

Data analysis

All the interviews were transcribed verbatim. Data was analysed using the ‘Framework’ method (Ritchie and Spencer 1994), developed at the UK National Centre for Social Research. Initial themes and concepts were identified through reviewing the data. These were then used to construct a thematic index. All the material was indexed, such that each phrase or passage was assigned a label. Thematic charts were constructed, the chart headings evolving from the indexing process. The labelled data were then summarised and synthesised into these matrices. This matrix based method of analysis allows both thematic and ‘case’ based analysis, enabling systematic exploration of the range and pattern of views and experiences. All the different stages in the iterative analytic process inherent in the ‘Framework’ method were carried out through discussion and collaboration between the first author and a senior researcher, helping to avoid bias. For example, the senior researcher selected a portion of charted material in order to comment on the analytic themes that were being drawn out of the data. Where there were disagreements in interpretation, these were discussed until a consensus was reached.

Results

What are the causes of friendship loss after a stroke?

There were a variety of reasons that people gave for why they had lost friends such as loss of shared activities, reduced energy levels, poor mobility, unhelpful responses of others, environmental barriers, aphasia, and the changing social desires of participants. In some cases, it was clear that a friend was 'lost' to a participant, for example, the friend had not contacted them since the stroke. In many cases, however, it was less clear cut: participants may have less or no contact with a person post stroke, but still consider them a 'friend'. Thus this section explores not only the reason why friends were 'lost', but also why participants could feel less close to friends, or saw them less frequently.

Loss of shared activities

A major change in how friendships function post stroke is the loss of shared activities. Although the purpose of some of these activities may not have been primarily sociable, in losing the activity participants also tended to lose the friends and social contacts that was a part of the experience. There was a wide range of lost activity described, including work, attending religious services, sport, cultural activities, organised groups and other social or semi-social events.

Reduced energy levels

People felt exhausted post stroke, even in this chronic phase, which impacted on their desire and ability to socialise. Even those with mild strokes described restricting social engagements and coming back early from social events. Exhaustion could also have a negative impact on

socialising in the home. An example is Bridget, 74 years old and living on her own.

Following the stroke, she was housebound and often exhausted. Although lonely and wanting company, she found herself pushing away potential guests, as the following excerpt illustrates:

'How can you invite somebody, and all of a sudden, you go to sleep, and you can't comprehend or have tea with them or something? It's not very nice you know. Somebody did ring me up one day, and say, you know, come and I'll bring the cakes. I said, oh, not today, I'm, you know, otherwise occupied, that's what I had to say. But when I put the phone down I cried because I had to go to bed.'

Exhaustion also made it harder for participants to initiate or arrange social events. An example is Patricia. Friendships which relied on her taking the lead on organisation had slipped away from her since the stroke, as she no longer had the energy to take on this role: *'I can't be bothered to phone them [a group of artist friends] and make arrangements and go out with them any more...I just don't have the energy level, it's really quite simple.'*

Poor mobility and other physical symptoms

For those who were housebound, they were only able to see friends who were prepared and physically well enough to come to them. Since friends are usually of the same age, for some of the older participants this could mean that face to face contact was no longer possible. Even those able to leave the house independently could report being fearful of having a fall, meaning they stayed at home more than they used to.

Other physical symptoms also impacted on people's social lives, both directly (for example, difficulty writing making correspondence with old friends no longer possible), or indirectly (visual field disturbance meaning they could no longer drive).

Unhelpful responses of others

The most extreme negative response was where the participant felt that a friend, or even an entire friendship circle, had abandoned them after the stroke (*'When I was still alright, I didn't have this stroke on one side, everybody likes me, once I got the stroke, no-one care about me any more.'*) Other unhelpful responses reported included friends who ridiculed them; friends who told them how to feel; friends who pitied or patronized them. For example, one participant described how work colleagues' attitudes had changed since he came back from the stroke: *'The young chaps at work tend to feel a bit more, how can I say, sorry for me to some degree, which I don't like really, they try to treat me as, you know, a little bit somebody who's, ah bless him, he's got something wrong with him.'*

Environmental barriers

Using public transport could become more difficult post stroke, and it was universal for participants to avoid lengthy or complicated travel. Similarly other factors like anxiety about 'difficult' buildings with steps or insufficient toilets, or a lack of suitable seating, could deter participants from going out.

Aphasia

Those with aphasia appeared to have the most negative experiences in terms of other people's responses. Several reported others laughing at them or mocking their speech, which could

lead to a sense of shame or embarrassment, and an avoidance of talking. (*‘They laugh at me if it mistake... That’s why sometimes I just keep quiet [crying]’*). There was no other physical symptom which was similarly mocked. The most extreme negative response of ‘deserting’ the participant or cutting off contact altogether was again only reported by those with aphasia. They were also more likely to experience difficulties keeping in contact with friends who lived abroad, as writing and speaking on the telephone could be difficult. Finally, those with aphasia were the most likely to say that even where they still saw friends, the substance of the friendship had been altered, for example, humour could be more difficult, conversations were less likely to be two way, it could be harder to join in or get their point across.

Although there were people with aphasia who had not lost friends, all the participants in this project who had lost their entire friendship networks had aphasia.

Changing social desires of participants: *‘I seem to be closing in on myself’*

Part of the reason why friendships changed post stroke appeared to stem from the changing social desires of the participant. In part, this was a response to the many factors described above: socialising with friends becomes a less attractive option if one is fatigued, walking is more effortful, communicating is a challenge, or the logistics of travelling to and attending an event become more onerous. However, there were also more internally driven reasons given by participants as to why they no longer had the same desire to see some or all of their friends and acquaintances. There was a sense that many participants were ‘closing in’ on themselves, and wanting to withdraw from the wider world. They gave a variety of reasons for this phenomenon.

Participants described how they felt less good company now: if previously they had felt themselves to be witty and fun, they might now feel boring. For example, one participant said he worried that he will seem dull, out of date, and less knowledgeable now that he spends so much more time at home and is not out and about working or at various cultural events.

There was also a reluctance to have others see them unwell or disabled: they worried that others would dismiss them, value them less, or pity them. Some spoke of feeling ashamed or self-conscious. Even those who did resume social activities could keep themselves semi-detached to avoid others noticing the extent of their disability. An example of someone who resumed an activity but felt removed from social contact is 58-year old Edward. Before his stroke he had taken up archery, becoming *'quite good'*. He had only recently gone back and struggled with the coordination required: he felt he was now *'absolutely useless with the shooting'*. He described the impact this had on him:

'And you tend to feel a bit more vulnerable then, you think, Oh God, are people looking at me, you know, he's a total waster coming up here, and you got all these people round you thinking "Oh God", and I tried to stay back, away from people, so that I wasn't involved.'

Many participants described feeling more introverted. An example is 74-year old Gordon. He knew many people locally, having lived in the same house for over 20 years. Before his stroke he said *'[I] used to go out so much before, I used to know everybody'*, and described himself as outgoing. Following the stroke, although physically able to walk, he commented, *'I just don't feel like going out now...just I seem to be closing in on myself'*. Others describe how going out to meet people could be a cause of anxiety and fear. In comparison, staying at home could make a person feel secure. The stroke could make them reassess their own vulnerability,

and redraw the boundaries of where they felt comfortable. This is illustrated by the following quote:

'I felt quite safe inside the house and I didn't really feel a desire to go outside, I couldn't see any point in going outside. Um. You become quite introvert and frightened when you have [a stroke], because you realise you're rather vulnerable.'

Feeling unwell, depressed, anxious, self-conscious, or the effort of concealing the stroke could all make social situations less enjoyable. Further, some of the functions of social activity were arguably lost. Social gatherings that had been fun, and taken the participant's mind off any worries, could now be stressful and heightened their awareness of their own difficulties. Activities where they had previously enjoyed 'expert' status, bolstering their self-esteem and status, could now have the opposite effect. Loss of reciprocity could also challenge their sense of social identity. A common refrain was that people could no longer be bothered with many social activities.

If in part participants were withdrawing from their wider social worlds out of a sense of vulnerability or the emotional discomfort of socialising post stroke, there was another strand of reasoning that also emerged from the data. There appeared to be a revamping of what was important, which was reflected in a new selectivity about social engagement. There was often a preference for seeing family and only close friends. Interactions with acquaintances or strangers appeared to be less valued post stroke. One participant said he used to find meeting new people exciting whereas now he feels it's a waste of time; another described how since his stroke he no longer has tolerance for '*aimless chatter*'. By contrast, several described the comfort they have found in talking '*the same old rubbish*' with long established friends.

It was also common for people to report that since the stroke they preferred meeting up with friends one to one or in small groups. Large crowds and noisy gatherings were often avoided. This phenomenon is illustrated by Gerta, 83 years old and living on her own.

'I have been invited to some meals out before Christmas, and it was often very noisy in some of the restaurants, you know, and in some places, that's the point where you feel you have changed, one is changed a bit. One is more inclined to talk to one person, and not to mix too much in a big crowd.'

The stroke could enable participants to re-evaluate what they were looking for in their social worlds. This is illustrated by 18-year old Pratik. He described how the stroke was a turning point, and a catalyst for change. Following the stroke he was no longer prepared to be in social situations which made him unhappy, and he consciously chose to lose touch with a group of friends who he felt undermined him.

Participants who reported a change in their desire to socialise lost many, sometimes all, of their friends and acquaintances. It appeared that these internally driven reasons were a major factor in understanding the reason why friendship loss is so frequently described post stroke.

What factors help to protect friendships?

Feeling 'close' to a friend

The greatest protection of all was the quality of the friendship prior to the stroke. Those who felt very close to someone generally succeeded in maintaining such a friendship, even where

there were various other obstacles. The friends least likely to be lost were those who *'cared'*, *'showed concern'*, with whom they had shared history, and who knew them well enough that they didn't need to feel self-conscious, for example, about dropping off to sleep when together. Conversely, those on the periphery of their social network were more vulnerable to being lost.

Distance

Living locally was a strong protective factor for the friendship. It meant there was no need to negotiate public transport and that visits could be more spontaneous.

Availability of the friend

Various factors affected how 'available' a friend would be, such as whether they were retired, were mobile, could drive, were in good physical and psychological health, and had few other commitments.

Not activity based prior to the stroke

Those friendships that were partially or wholly based around meeting up in each other's homes appeared to be more robust post stroke than those where the participant only saw the friend when out and about, for example, when going to an activity.

Regular, supportive groups

Several participants described going to a particular café, pub, club or group at least once a week, in some cases, almost every day. Thus there was an element of 'scaffolding', whereby

the meeting place and time was regular, which made maintaining such friendships easier. Participants described talking to whichever of their friends happened to have come along that day. This method of meeting friends avoids the necessity of initiating or organising contact, and although pre-arranged was often relatively informal

It was possibly the most supportive type of group the participant could attend, since it was likely they would know all members, which could help if they were coming to terms with new disability. There may have been something protective, too, about the fact that the friends all knew each other in these set ups, thus could potentially support one other in supporting and accommodating the participant.

In a similar vein, friendships made through church or mosque also had a protective ‘scaffolding’: so long as the participant was physically able to attend religious services post stroke, they would be met by a supportive community on a regular basis.

Family friends

Where a friend knew the spouse, the participant could be enabled to remain in contact with them since it was the spouse who would be likely to be organising the contact, and, for example, inviting them to the house and hosting them.

Having a ‘friends-based’ social network prior to the stroke

For these participants, friends, as opposed to family, occupied a central role in their social network prior to the stroke, and were likely to be the main source of emotional and

companionship support. Almost all those with friends-based social networks pre-stroke reported maintaining their most important friends, if not all their friends, post stroke.

The case example below illustrates how these protective factors can help someone maintain their friendships, even where they have aphasia.

Retaining friends despite having aphasia

Andy was 69 when he had his stroke, leaving him with moderate aphasia. Despite his language difficulties, he felt the stroke had not changed his friendship patterns. He is an example of someone who had many of the ‘protective’ factors listed above: he had a long-established and supportive group of friends who lived locally, whom he saw at a nearby club on a regular basis; he had a ‘friendship-based’ social network prior to the stroke; the stroke had not affected his mobility; he was open about his aphasia and strategies that helped; and he did not display any tendencies to ‘close in’ on himself: *‘Don’t afraid, keep talking, don’t shut away, yes, yes. I don’t do that. I wouldn’t do any of that.’*

How is friendship loss and change perceived by the individual?

There was much variation in how people felt about their changing social situation: although some were devastated, not everyone lamented the changes.

The participants who were the most hurt by the changes were those who felt rejected or mocked by people they had thought were friends. The hurt could additionally be accompanied by bitterness, a lack of comprehension about why their friends had abandoned them, and anger or defensiveness.

More commonly, participants did not express bitterness or hurt, but did feel a sadness that they were no longer in such frequent contact with friends and acquaintances. They missed activities and social events that they had given up, such as dancing classes or going to football matches, or even their daily walk.

Sadness was often tempered by the hope that their situation would improve. Many participants still hoped that in the future they would be able to resume various activities. An example is Pablo, 63 years old with aphasia. He described friends he knew through fishing. Since his stroke, he had not been able to go fishing and no longer saw these friends. However, he still considered his fishing friends to be his 'friends'. He was hoping that one day he will go fishing again, and the friendships will be picked up at that point. Thus although he was sad that he could not go fishing, he did not feel he had 'lost' his friends. Indeed, a recurrent theme was that people didn't feel less close to friends and social contacts, just didn't see them so often. While they might wish they could see them more, it was not hurtful, did not challenge their concept of friendship.

Participants also expressed sadness about the ways in which even close friendships had needed to change post stroke. Particularly for those who were housebound, an element of reciprocity could be lost. This is illustrated by Adebomi, 68 years old with aphasia. She was now reliant on friends visiting her, and when they arrived, not only could she not offer them a meal (she had previously been a keen cook), she couldn't even make them a cup of tea, all of which she found upsetting. Many of those with aphasia described frustration and distress relating to the difficulties in having conversations with friends.

There were also those who were positive about losing friends and acquaintances: they no longer wanted to be out and about mixing with people, preferring to limit their social interactions.

Finally, a small subset of participants felt that their friendships had been strengthened by the stroke, which was a source of happiness to them.

Unpacking the relationship between depression and loss of friends

A theme emerging from the interviews was the prevalence of depressive type symptoms in this chronic phase post stroke such as feelings of sadness, despair and anxiety, having no energy, lack of interest or motivation to engage in activities, low self-esteem, and a sense of feeling stuck or 'lifeless'. Such depressive feelings could make a person disinclined to socialise: a wish to withdraw and retreat from others was common as described above. The lack of social contact, however, arguably intensified the feelings of depression, such that a vicious cycle could be set up. This is illustrated by the following case example. Before the stroke, 62-year old Patricia was a journalist who prided herself on her fluency and humour. The stroke left her with mildly reduced fluency which in turn meant that in the months post stroke: *'I didn't feel that I had the right level of conversation to hold myself up in company.... I didn't feel that I could I suppose inflict myself. I didn't want to go to places and not be able to contribute in every way, I didn't feel I could.'* Prior to the stroke she had a busy social life, post stroke this was severely restricted. She also described her depression, where life seemed *'very dull and dim'*, where she couldn't see a way out, felt despair, no longer had any energy or interest in life. She described the relationship between reduced contact and depression: *'I didn't go [out] because I felt insecure and I felt insecure because I didn't go out. So it kind of*

built up to this [feeling depressed].’ Sitting at home, doing nothing, made her feel lonely: ‘I hate loneliness. Loneliness frightens me more than anything at all.’

Discussion

This small-scale but in-depth study explores why friendship loss is common post stroke. Various reasons were given by participants, such as fatigue, poor mobility, loss of shared activities, environmental barriers, aphasia, unhelpful responses of others, and the changing social desires of participants. Factors which helped to protect friendships included: living locally, quality of the friendship, availability of the friend, where meeting up had been home-based rather than activity-based prior to the stroke, and where the participant had a ‘friends-based’ social network prior to the stroke.

One of the main findings of the project was that many participants reported a change in their desire to socialise, and that this withdrawal from their wider social world, or ‘closing in’, was associated with losing all or most of their friends. Other qualitative studies have also described a reluctance to socialise post stroke (Parr *et al.* 1997, Dowswell *et al.* 2000). The reasons why people avoided contact included feeling dull, vulnerable, anxious, and depressed. Fatigue and feeling non-specifically unwell were also given as reasons why people did not want to see others, and in some cases could also be argued to be part of a picture of depression. These findings, then, support the existing literature that documents the close association between depression and reduced non-kin social contact in the long-term post stroke (Astrom *et al.* 1993, Hilari *et al.* 2010). Several authors have commented that the direction of causality between depression and social withdrawal is unclear (Hartup and Stevens 1999, Fiori *et al.* 2006): those who are depressed may well find it difficult to maintain

friendships; equally, being socially isolated is likely to exacerbate depressive symptoms. The current project would seem to indicate that in many instances a ‘vicious cycle’ is set up post stroke. There is some suggestion that those with strong friendship bonds pre-stroke are protected from this occurring: those with ‘friends-based’ social networks prior to the stroke were unlikely to experience this social withdrawal post stroke. In part, this may be because their friendships were more well-developed and supportive; they also had fewer family resources to fall back on. The larger study from which these participants were drawn also found that pre-stroke social factors were important: loneliness and low satisfaction with one’s social network *prior* to the stroke were both predictive of psychological distress six months post stroke (Hilari *et al.* 2010).

While isolation and loneliness are clearly unwelcome outcomes, some acceptance of more selective socialising could be argued to be adaptive. Many participants described a change in what they wanted from their social lives, preferring to meet with family and old friends rather than acquaintances. This is in line with the socioemotional selectivity theory (Carstensen *et al.* 1999) which suggests that when time in life is perceived as unlimited, people tend to prioritize goals that optimize the future, such as seeking out novel social partners who may provide information or expand horizons. However, when time is perceived to be limited social motivations change, and present-oriented goals that relate to emotional meaning are prioritized. Thus older people (Fredrickson and Carstensen 1990) and those with terminal illness (Carstensen and Fredrickson 1998) have been shown to prefer contact with immediate family and close friends. Arguably this could be extended to apply to those participants in the present project who described feeling newly vulnerable and aware of their own mortality. According to this theory, selectively reducing social contact in such circumstances is adaptive, and results in greater emotional well-being. Other authors have also argued that some of the

benefits of friendship, such as enhanced self-esteem and well-being, may be lost in situations where, for example, reciprocity is compromised (DuPertuis *et al.* 2001). Certainly, in the present study participants did describe how some social situations such as parties or sporting activities, instead of bolstering their self-esteem and identity as had been the case prior to the stroke, could have the reverse effect, leaving them feeling *'the weaker member of the pack'*.

One of the reasons given for losing friends was the loss of shared activities. This complements the finding that post stroke a reduction in social activities is common (Angeleri *et al.* 1993). Participants also cited poor mobility and other physical symptoms. This is no surprise: those with more severe disabilities typically have smaller social networks (Litwin 2003). However, what also emerged from the data was the prevalence of reduced social networks even for those who had apparently made a 'good' recovery. This is in line with previous research which has found that a significant proportion of long-term stroke survivors do not return to their pre-morbid social life even after regaining their physical independence (Labi *et al.* 1980), and that restriction of activities is not significantly associated with physical disability (Greveson and James 1991). Certainly in this project there were participants with pronounced post stroke disability, including those who were housebound, who retained friendships. In a sense, it is a similar picture with aphasia: although those with aphasia were more likely to lose friends, there were examples of people with even severe aphasia who had managed to retain their core circle of friends despite the language difficulties. What appeared to make it possible for those with aphasia, and also those with more pronounced physical disabilities, to retain their most important friendships despite the inherent difficulties was to have a string of protective factors: a well-developed and supportive circle of friends, friends who lived locally and were in physical and psychological good health, friends without too many other time-consuming commitments, friendships not based primarily around activities.

Crucially, perhaps, there was also a desire to maintain contact with their friends coming from the participant. When asked what friends meant to him post stroke, a 48-year old participant with severe aphasia spent over six minutes writing his reply: *'They are the only think [thing] I have.'*

A final observation from the dataset relates to the direction of loss. Is it the friends who are deserting the stroke survivor, or is it the stroke survivor who no longer wants to see the friend? With the exception of those with aphasia, it was in fact rarely reported that a friend had 'abandoned' a participant. In fact, the use of the phrase 'lost friends' is perhaps misleading: participants did not usually speak about their friendships in this way. Rather they described friends who they no longer saw so frequently, or at all, but who they still liked. There was an acceptance that in giving up activities, whether this be an organised group, going to the pub or a party, or just walking to the local corner shop, they would no longer see certain people.

Strengths of the study are the robust sampling procedure ensuring that a diversity of experience was captured; the inclusion of people with aphasia; and a methodology which provided rich in-depth data. In terms of limitations, the timing of the study (8 to 15 months post stroke) may have precluded proper investigation of the role and value of new friendships formed after the stroke: although some participants had joined new social activities, such as stroke clubs, none reported acquiring new friends post stroke, possibly reflecting that not enough time had elapsed for their formation. Another limitation of the study is that only two participants were recruited who were under the age of 50, making it hard to draw conclusions about the social experiences of the younger stroke population. Finally, participants were encouraged to define and explore friendships in their own terms, and on occasion described

friendships with paid contacts, particularly carers: this material is not analysed in this paper. In terms of generalising the findings, caution needs to be exercised. This study explores the experiences of those recruited through one inner-city teaching hospital: the relevance of the findings to other contexts is dependent on the extent to which they are judged to explain the phenomenon studied.

Clinical implications and future research

One of the findings from this research was that barriers to maintaining friendships were as likely to be internal as external. Given the close relationship between depression and social isolation, possibly leading to a 'vicious cycle', interventions targeting this cycle may be effective. This may take the form of addressing the depression. Alternatively, more social approaches to therapy for example targeting participation may be helpful (Pound *et al.* 2000).

Another reason for reduced contact with friends was the loss of shared activities. This would suggest that making work, education and leisure pursuits more accessible may provide new social contacts post stroke, which in turn would be likely to reduce isolation and depression. However, given the vulnerability and anxiety expressed by many participants, it is possible that such new activities would only become truly accessible if people were given psychological as well as practical support in accessing them. Further, not every participant wanted such extended social contact, and even those that did spoke of a 'balancing act', between pushing themselves to engage with others, and recognising new limits, for example, as a result of exhaustion.

Various authors have suggested that existing conversation partner programmes, aimed at training spouses and other family members, could be extended to training and supporting

friends, and that this may be beneficial for those with aphasia (Cruice *et al.* 2006, Davidson *et al.* 2008). While this may be true in the specific case of aphasia, it seems unlikely that therapy targeting friends would be helpful in the wider stroke population, as it was rare that it was primarily the actions and attitude of the friends which caused a friendship to be compromised.

In terms of future research, it may be helpful to follow how friendship patterns develop in the longer term after a stroke, in particular, unpicking the potential benefits of forming new friendships and acquaintances. Further investigation could also explore friendship change and loss from the perspective of the friend, particularly for those with aphasia. Finally, research could explore more fully how young stroke survivors perceive friendship change.

Conclusion

This study used in-depth qualitative interviews to explore systematically why people lose friends following a stroke. Reasons given include loss of shared activities; fatigue; unhelpful responses of others; environmental barriers; and changing social desires of the participants. Roughly one third of the sample had aphasia: those with aphasia are often excluded from stroke studies, but yet are reported to face particular challenges in retaining friends. In this project, aphasia was indeed reported as a factor that made retaining friendships more difficult and could be a cause of hurtful negative reactions from others. Another major factor associated with friendship loss appeared to be the extent to which the individual was closing themselves off from social contact. This finding suggests that for many people post stroke effective intervention strategies may be those that support the individual in moving from social withdrawal to a desire to re-engage.

What this paper adds

It is well documented that people are at risk of losing their friends after a stroke, particularly those who have aphasia. Further, those who do suffer friendship loss are at higher risk of depression. However, it is not clear *why* people lose friends.

This study found that the main reasons for losing friends were: changing social desires especially a sense that many participants were ‘closing in’ on themselves; aphasia; loss of shared activities; reduced energy levels; physical disability; environmental barriers; and unhelpful responses of others. Successful intervention may need to take into account the multiple reasons for friendship loss, including recognising new social preferences post stroke.

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Figure One: 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*	♂; age: 63; (aphasia) Friends: 20 ♂; age: 58; Friends: 1	♀; age: 82; Friends: 1.5 Living alone	♀; age: 65; Friends: 20	♂; age: 74; Friends: 5	♂; age: 57; Friends: 4	♀; age: 76; Friends: 4; Living alone ♂; age: 75; Friends: 2
Moderate social support*	♂; age: 65; Friends: 9 ♂; age: 65; (aphasia) Friends: 0	♀; age: 68; (aphasia) Friends: 0 Living alone ♂; age: 66; Friends: 3	(n = 0)	♂; age: 76; Friends: 1 Living alone	♂; age: 65; Friends: 0	♀; age: 86; Friends: 3 Living alone ♂; age: 69; (aphasia) Friends: 7 ♂; age: 76; Friends: 5 ♀; age: 90; Friends: 2-3
Poor social support*	♂; age: 58; (aphasia) Friends: 0; Living alone ♂; age: 48; (aphasia) Friends: 5; Living alone ♂; age: 63; (aphasia) Friends: 4-5	♀; age: 66; (aphasia) Friends: 0 Living in nursing home	♂; age: 18; Friends: 1	♀; age: 74; (aphasia) Friends: 4 Living alone ♀; age: 74; Friends: 2 Living alone ♀; age: 78; Friends: 4-5	♀; age: 62; (aphasia) Friends: 4	♀; age: 83; Friends: 3; Living alone ♂; age: 68; Friends: 3

Explanatory note: * **Social support** as measured by the MOS Social Support Survey six months post stroke (Sherbourne and Stewart, 1991): participants grouped according to whether they scored in the top, middle, or bottom third of the population;

Friends: number of close friends reported at six months post stroke, defined as ‘people you feel at ease with and can talk about what is on your mind’.

Domestic situation: Participants living with family members unless otherwise stated.

Table 1: Participant characteristics

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 (British)	15
	White (non-British)	6
Marital status	Married - Has partner	16
	Single	5
	Divorced - Widowed	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	None	18
	Dysarthria	1
	Aphasia	10