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A typology to explain changing social networks post stroke

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Conflicts of interest

None

Abstract

Purpose of the study

Social network typologies have been used to classify the general population but have not previously been applied to the stroke population. This study investigated whether social network types remain stable following a stroke, and if not, why some people shift network type.

Design and Methods

We used a mixed methods design. Participants were recruited from two acute stroke units. They completed the Stroke Social Network Scale (SSNS) two weeks and six months post stroke and in-depth interviews 8-15 months following the stroke. Qualitative data was analysed using Framework Analysis; *k*-means cluster analysis was applied to the six month dataset.

Results

87 participants were recruited, 71 were followed up at six months, and 29 completed in-depth interviews. It was possible to classify all 29 participants into one of the following network types both pre and post-stroke: diverse; friends-based; family-based; restricted-supported; restricted-unsupported.

The main shift that took place post stroke was participants moving out of a diverse network into a family-based one. The friends-based network type was relatively stable. Two network types became more populated post stroke: restricted-unsupported and family-based. Triangulatory evidence was provided by *k*-means cluster analysis, which produced a cluster solution (for n=71) with comparable characteristics to the network types derived from qualitative analysis.

Implications

Following a stroke, a person's social network is vulnerable to change. Explanatory factors for shifting network type included the physical and also psychological impact of having a stroke, as well as the tendency to lose contact with friends rather than family.

Key words: social networks, social isolation, analysis – mixed methods, friendship, chronic illness

Introduction

Stroke is a leading cause of complex disability in older adults (Adamson, Beswick, & Ebrahim, 2004); around 75% of people who have a stroke are aged over 65 (National Audit Office, 2010). Following a stroke, a person is at risk of losing contact with friends and their wider social network (Northcott, Moss, Harrison, & Hilari, 2015; Vickers, 2010). They also take part in fewer social activities (Cruice, Worrall, & Hickson, 2006; Fotiadou, Northcott, Chatzidaki, & Hilari, 2014), and the family unit is placed under strain (Northcott, Moss, et al., 2015; Winkler, Bedford, Northcott, & Hilari, 2014). Yet the social impact of having a stroke varies: a subset appear relatively able to preserve important elements of their kin and non-kin social contact (Northcott & Hilari, 2011). The current project aimed to develop a social network typology in order to provide an explanatory framework in which to explore why some people's social networks are more vulnerable than others post stroke, and whether there are protective factors.

The social relationships a person has can profoundly impact on mood, life satisfaction and physical health. A meta-analysis examined the impact of social relationships on illness-related mortality (Holt-Lunstad & Smith, 2012). The analysis included 148 studies of 308,849 participants who were followed for an average of 7.5 years. On average, people with stronger social networks had a 50% increased likelihood of survival; the effect was strongest in those studies that used complex measures of social integration (for example, measuring frequency and density of social contact) rather than those studies using a binary measures (e.g. whether living alone). Furthermore, the quality of social relationships has been consistently associated with life satisfaction (Pinquart & Sorensen, 2000), with those who perceive themselves poorly supported at greater risk of developing depression (Teo, Choi, & Valenstein, 2013). These patterns have also been observed in the stroke population. A recent systematic review (n = 4,816) found that both low perceived social support and reduced

social network were consistently associated with depression, worse quality of life, and worse physical recovery (Northcott, Moss, et al., 2015). It is therefore of concern that those who have a stroke are at risk of becoming isolated.

Given the adverse consequences of becoming isolated post stroke, it is important to understand the reasons why some people experience a contraction of their social network, while others are able to maintain contact with diverse sources of support (e.g. family, friends, local community). Developing a social network typology may provide a useful framework for understanding these variations in response. Further, the type of network a person belongs to has been shown to be an important factor in how a person responds to aging and ill-health, and the patterns of support they both seek and receive (Machielse, 2015; Wenger, 1994). Developing a clearer understanding of how social network patterns change following a stroke may therefore enable services to support the social well-being of people post stroke more effectively.

Social network research has distinguished major network 'types' through examining key elements, such as frequency of contact with kin and non-kin network members . Despite the heterogeneous methodologies, for example, Framework Analysis applied to qualitative interviews (Spencer & Pahl, 2006) or *k*-means Cluster Analysis applied to population-based survey data (Litwin, 2001), previous research has consistently found the following broad network types: a network type characterised by frequent contact with diverse sources, including family, friends, neighbours and often also community involvement; a network where friends are the key source of support and contact; a family-based network, where a person has more contact with family than friends; and a restricted network, distinguished by there being few social contacts (Fiori, Antonucci, & Cortina, 2006; Li & Zhang, 2015; Litwin, 2001; Litwin & Shiovitz-Ezra, 2011; Spencer & Pahl, 2006; Wenger, 1994). Depending on the variables used to define the typology, additional network types have also

been found, for example, a network type characterised by close contact with neighbours with few friends and family (Spencer & Pahl, 2006; Wenger, 1994). Those in 'diverse' networks, thus having frequent contact with both family and friends, consistently have higher morale and subjective well-being than those in more restricted network types (Fiori et al., 2006; Li & Zhang, 2015; Litwin, 2001; Litwin & Shiovitz-Ezra, 2011).

Most social network typology research is cross-sectional. However, both Wenger (1994) and Li and Zhang (2015) followed a cohort of older people thus providing insight into how social networks change over time. Both these studies found that people most commonly shift into either family-based or restricted networks. In terms of predicting who will shift network type, Li and Zhang (2015) found that those with worse health were at a higher risk of shifting network type; while Wenger (1994) documented that increasing frailty and old age were factors. However, Wenger (1994) also noted that most network types remain stable and as such represent a life-long adaptation with only a small percentage shifting each year.

Social network typology work has not yet been applied to the stroke population. A stroke potentially represents a challenge to the functioning of a person's social network (Northcott, Moss, et al., 2015). Tracking people with stroke over the first year post onset therefore provides an opportunity to explore in more detail the mechanisms by which people potentially shift network, and what factors enable some people to maintain their pre-stroke network type. In order to determine whether the developed network typology was a reasonable sectoring of the social world, we were also interested in triangulating our findings using mixed methods. Triangulation, where two different methods lead to similar findings, potentially increases confidence in the findings (Singleton Jr, Straits, & Straits, 1993). Specifically, if both qualitative and quantitative methodologies produced social network types with similar characteristics it would provide reassurance as to the validity of the typology.

This study addresses the following three research questions: Which network types are stable post stroke and which are vulnerable to change? What factors explain why a person changes network type? Will a similar network typology be found when using qualitative and quantitative methodologies?

Design and Methods

This study is primarily a qualitative study: qualitative methods were used to develop a typology, explore network shifts, and explanatory factors for change. Quantitative methods (cluster analysis) were used to provide triangulatory evidence for the qualitative typology. The study formed one part of a larger study exploring quality of life and social relationships post stroke (Hilari et al., 2009; Northcott & Hilari, 2011). Ethical approval was gained by the appropriate National Health Service local ethics committees; pseudonyms, replacement terms and vaguer descriptors are used throughout this paper to preserve anonymity.

Participants

Participants were recruited from two acute stroke units in metropolitan teaching hospitals. People were eligible to take part if they were over 18 years old; had a first stroke; and were admitted to hospital for at least three days. Exclusion criteria included: not living at home prior to the stroke; severe co-morbidity, for example, advanced cancer; unable to give informed consent; history of mental health problems or cognitive decline; non-fluent English speaker pre-morbidly. Those with any severity of expressive aphasia and mild-moderate receptive aphasia could self-report on the measures used. However, those with very severe receptive aphasia (scoring <7/15 on the receptive domains of the Frenchay Aphasia Screening Test (Enderby, Wood, Wade, & Hewer, 1987)) were asked to nominate a proxy. Proxy responses are analysed elsewhere.

A subset was purposively selected to take part in in-depth qualitative interviews. When selecting who to invite to the qualitative arm of the project, a sampling matrix was used in order to systematically optimise the range and diversity of relevant characteristics (Ritchie, Lewis, & Elam, 2003). Primary criteria included: stroke severity, age (whether aged over 65 or not; secondary target of recruiting a minimum of five people aged over 80), and perceived social support. Secondary criteria included additional social factors (living arrangements, size of network, number of close friends), gender and ethnic background. Those with aphasia were preferentially included to ensure they were adequately represented (see on-line Appendix A for further details).

Procedures and methods

Participants' social networks were assessed within two weeks of having the stroke (baseline), and again six months later. The outcome measure used was the Stroke Social Network Scale (SSNS) developed as part of this project and validated on stroke survivors with and without aphasia (Northcott & Hilari, 2013). During the baseline assessment, participants were asked to reflect on the month prior to their stroke. The SSNS consists of five subdomains: children; relatives; friends; groups; satisfaction with social network. There is good evidence for the scale's internal consistency ($\alpha = 0.85$), acceptability, validity and sensitivity to change. There are 19 items, and questions focus on frequency of contact (either face to face or remote e.g. via telephone, email, letter), proximity, quantity (e.g. number of close friends, number of close relatives), and satisfaction (e.g. with overall social network). Overall scores range from 0 to 100, with higher scores indicative of a better functioning social network (Northcott & Hilari, 2013).

At approximately 12 months post stroke a subset of participants then took part in in-depth interviews. A topic guide was used (see on-line Appendix B). The order in which topics were covered varied from participant to participant, following in an organic way from participant

responses. The interviews explored participants' social networks and how these had changed since the stroke; experiences of receiving and giving support; and probing of the impact of the stroke on family relationships and friendships. Interviews took on average 65 minutes and were audio recorded. Interviews were carried out by the first author (SN) who is a speech and language therapist with experience of working with people who have aphasia. Two early interviews were listened to by a senior researcher who gave feedback helping to ensure the interviews were non-biased and enabled participants to explore topics fully. The researcher also kept field notes which included contextual information as well as reflections on the influence of her own background on the research process.

Qualitative data analysis

All the interviews were transcribed verbatim, and analysed using the Framework method (Ritchie & Spencer, 1994). Several steps were followed in using this approach (Spencer, Ritchie, O'Connor, Morrell, & Ormston, 2014). Initial themes and concepts were identified through reviewing the data. These were then used to construct a thematic framework. The framework contained eight main themes (e.g. Theme 3: Friendship post stroke), under which more detailed subthemes were nested (e.g. Subtheme 3.2: changes to friendship post stroke). The transcribed material was then indexed, thus a decision was made for each phrase or sentence as to which section of the framework it belonged to. Having indexed the material, thematic matrices were constructed. Each main theme was a separate matrix, and each subtheme a separate column, while participants were assigned a particular row. The indexed data was then summarised and synthesised, and entered into the appropriate cell in the matrices. The advantage of this matrix-based system is that it enabled systematic cross-case and within case analysis, facilitating descriptive accounts of the range and diversity of experiences. Further, since the matrices link back to the transcripts, it allows the analyst to 'move back and forth between different levels of abstraction without losing sight of the raw

data' (Spencer et al., 2014, p. 283). In order to avoid bias, a senior researcher was involved in all stages of analysis, for example, reviewing charted material in order to reflect on the emerging analytic themes.

We used this matrix-based analytic system to facilitate the development of a social network typology. We aimed to create a multifactorial typology (i.e. a person was assigned to a network category as determined by several variables), where the network categories were discrete and independent of one another, thus an individual belonged only to one category. Our aim was that the emergent typology should be meaningful, easily recognisable, and capture important patterns. In determining relevant variables with which to classify participants, we were initially guided by the literature, research aims, and by a systematic analysis of the different elements identified within relevant subthemes. However, the process of establishing whether the typology 'fitted' with the dataset was iterative, requiring interrogation of the whole dataset, to ensure all participants could be assigned to a network category and that no participant in fact belonged to more than one network category. Where this was not the case, the variables or categories were refined, and the typology reworked. For example, we initially considered proximity as a variable as used in previous typologies (Litwin, 2001; Wenger, 1994). Yet in the present dataset it was rare that adult children lived close by, and this variable did not facilitate differentiating the network categories. A further consideration was that the typology needed to work with both pre-stroke and post-stroke data (i.e. it would be possible to categorise all participants at both time points). In analysing the reasons why people shift network type, we explored explicit explanations (i.e. those provided by the participants), as well as searching for 'linkages' within the data (where a particular phenomenon co-occurs in the dataset with another phenomenon), inferring possible explanations from the identified patterns of association.

In order to classify participants into social network categories, the primary source of information was the in-depth qualitative interview carried out at approximately one year post stroke and which included reflection on both their current and pre-morbid social network. However, we also referred to the Stroke Social Network Scale as administered at both two weeks and six months. The process of classification relied on the qualitative techniques described above.

Quantitative data analysis: cluster analysis

Cluster analysis is an exploratory data analysis tool which classifies multivariate data into clusters or subgroups (Burns & Burns, 2008; Hair & Black, 2000). The variables entered into cluster analysis were four of the five factors (six month dataset) which made up the Stroke Social Network Scale (Northcott & Hilari, 2013): Children; Friends; Relatives; and Groups. We did not include the Satisfaction domain in order to better match the qualitative typology where satisfaction was considered only in so far as it differentiated between different network members (i.e. satisfied with contact with friends versus children).

Hierarchical cluster analysis was used initially to determine the optimum number of clusters (Burns & Burns, 2008), at which point *k*-means cluster analysis was used. *k*-means clustering produces the number of clusters requested which are 'of the greatest possible distinction' (Burns & Burns, 2008). Since the variables employed (social network factors) did not all have the same variance, they were standardised prior to entry into cluster analysis (Hair & Black, 2000). In terms of interpreting results, ANOVA was used to determine the factors on which the clusters were differentiated. Further information on cluster analysis methodology is supplied in on-line Appendix C.

Results

Participants

Eighty-seven participants were recruited into the main study (completing the social network assessment), of whom 71 were followed up at six months. Of these 71 participants, 32 were selected to take part in in-depth interviews about a year post stroke (range 8-15 months): 29 consented, one declined, and two were no longer contactable. Participant characteristics are displayed in Table 1. At six months, the majority were white (80%), male (56%), and married/ had partner (53%). Eleven (16%) had aphasia. For the in-depth interviews, again, the majority were white (72%), male (59%) and married/had partner (55%). Ten (34%) had aphasia. On-line Appendix A shows how the participants fitted into the sampling matrix.

***insert Table 1 ***

Table 2 displays descriptive statistics for the Stroke Social Network Scale (SSNS). The overall score reduced from mean (SD) = 60.69 (15.22) at baseline to mean (SD) = 56.78 (15.44) by six months post stroke ($t(70) = 3.89$, $p<0.001$) . The only domain where there was significant change was the Friends domain, $t(70)=4.25$, $p<0.001$, while the Children domain ($t(70)=1.56$, n.s.) and Relatives domain ($t(70)=0.89$, n.s.) were the most stable.

insert Table 2

Qualitative analysis to develop a social network typology (n=29)

The variables used to classify participants to a social network category were as follows:

- Perceived amount of contact with children, relatives and close friends, and satisfaction with that contact;

- Composition of the network (relative number of kin versus non-kin, and close friends versus more casual social contacts) and perceived importance of different network members;
- Which network members were most likely to provide different types of functional support, for example, emotional or practical support, and the meaning this support held for participants.

Five network categories were derived using these variables. It was possible to classify all 29 participants in the qualitative arm of the project into one of these categories both pre and post stroke. The categories were defined as follows:

1. *Diverse network.* These participants had the most extensive social networks, comprising both kin and non-kin. They had close relationships with their immediate families, whom they saw frequently, as well as strong friendships.
2. *Friends-based network.* Friends occupied a central role in this network type. Friends were likely to be the main source of emotional support.
3. *Family-based network.* Family were the main source of support for these participants, and they had close relationships with several family members. Friends were not considered as important as family ties, and participants were unlikely to be in frequent contact with friends.
4. *Restricted-supported network*. These participants had limited social ties, and few or no close friends. Despite their relative isolation they felt well-supported by one or two family members, for example, a spouse or daughter.
5. *Restricted-unsupported network.* As with the above category, these participants had limited social ties. They either had no children, or did not live near a child; had few or no close intimate friends; and received very limited functional support from any source.

Which network types are stable post stroke and which are vulnerable to change?

Figure 1 displays the patterns of change that occurred post stroke. The three network types found to be most stable were: friends-based, family-based and restricted-unsupported. Around one third of participants shifted network type. The most common pattern of change was to move from a diverse network into a family-based one. Categories which became more numerous post stroke were family-based and restricted-unsupported. Nobody moved out of the restricted network types into a more supportive category following a stroke, nor did anyone acquire a diverse or friends-based network.

Figure 2 details the category membership of each participant before and after the stroke, as well as giving information on each participant's living arrangements post stroke, age, and presence of aphasia. However, since the sample was purposively selected to emphasise diversity it is therefore not representative of the parent stroke population and prevalence rates should be interpreted cautiously.

insert figures 1 and 2

What factors explain why a person changes network type?

Retaining or losing a diverse network

What determined whether a person retained their diverse network was the extent to which they maintained non-kin contact: the family element of their network remained constant and supportive. Factors which enabled people to keep their non-kin contact post stroke included: being able to leave the house (and therefore more able to access social activities and meet with diverse network members); not feeling withdrawn or depressed; the quality of their pre-stroke friendships; having friends who lived locally; and regular supportive groups including church membership. This is illustrated by Winnifred, a 65-year old. She had lived in the same house for 30 years, and had many local friends. Extended family also lived nearby. She

described her house as *'full… a lot of people here, always.'* She had recovered sufficiently to be able to leave the house, enabling her to attend church regularly, where she *'know everybody'*, and to go for short walks. She described adopting a positive outlook: *'you have a smile on your face, they too have a smile'*.

In terms of those with a diverse network who shifted into a family-based network, there were two sub-groups. One sub group had severe physical disability and could not leave their house without considerable assistance. This group still hoped for further recovery, and to resume social activities. An example is Tomasz, aged 66. Although his friends were important to him (*'I don't have 10% friends, they are 100% friends'*) his friendships had been altered by the stroke: he could not leave his flat without his son assisting him, and he found it *'rather impossible'* to be in receipt of his friends' goodwill rather than helping them. He now saw his friends *'rarely'*. He conceptualised changes to his social network as temporary, and lived in *'hope that tomorrow might be better.'*

The other sub group who shifted from diverse to a family-based network, as distinct from the above pattern, were not housebound. Instead, the primary factor appeared to be changing social desires, for example, feeling withdrawn, depressed, or hesitant about leaving the house. There was also a new selectivity about who they preferred to spend time with: seeing family and small intimate gatherings were preferred to large, noisy social occasions which appeared to hold less meaning for them post stroke.

Case example: moving from a diverse social network to a family-based one

Prior to the stroke *Peter* was a successful business man, had an active social life as well as a close relationship with his family. One year post stroke he had made a good recovery and was able to walk, although he still experienced extreme fatigue. He had handed over the family business to his son which he described as *'very traumatic'*. He rarely saw any of his old friends, preferring to see his close family. He explained '*I can't be bothered*' to socialise outside the family, fearing others might perceive him as '*the weaker member of the pack'*. He described feeling vulnerable and disinclined to leave the house.

Maintaining a friends-based network

All those who belonged to a 'friends-based' network pre-stroke retained this network type post stroke, with the exception of one participant. In some cases this was despite various risk factors for losing friends such as feeling withdrawn, having severe aphasia, losing shared activities including paid work, physical disability and exhaustion. While many did experience reduced social activity, friends were still the main source of support.

In terms of what enabled them to maintain this network type, one factor was that they had well-developed friendships prior to the stroke: they spoke about how long they had known their close friends, the experiences and interests they shared, that they felt understood, and the bond this created (*'As close as I will ever be to anyone. She totally understands absolutely everything… we're old horses together'*, Patricia, aged 62, speaking about a friend she had known for 25 years). Several participants also spoke of honesty and frankness within their most important friendships. Participants with a friends-based network all described the support and concern they received from their friends post stroke. This is illustrated by John, aged 76. He explained that the stroke hadn't changed his friendships (*'I'm lucky there,*

they're very good.') When asked to elaborate, he explained: *'Well, they're supportive, it's hard to explain what supportive means, I suppose, but it's this showing concern… it's the tone of voice, and how they ask me about things.'*

A further factor is that these participants had fewer family resources to fall back on: they either had no grown up children or troubled relationships with their children. The majority lived on their own. As such, they had more reason to maintain friendships. As noted by Leonisa, aged 74, *'When you are living alone, you cannot, you have nobody to talk, to laugh together, so when you are with the friends, it's nice.'*

The only person to shift out of this category had a distinctive profile: prior to the stroke she was in less good health, and had a smaller friendship base in part because good friends had either moved away or died. Post stroke she had become housebound and had significant discourse difficulties associated with her right hemisphere stroke. She developed a restricted-unsupported network and her main social contact post stroke was with her daily carer.

Case example: maintaining a friends-based network

Steve was in his 40s, working, living alone with no children. His primary sources of support were his close friends. He had a severe stroke leaving him with long-term mobility difficulties and severe expressive aphasia. While he lost touch with many acquaintances, he retained his most important friends, and described feeling close to them. When asked about his friendships, it took him over six minutes to write: *'They are the only think [thing] I have.'*

Maintaining a family-based network

Participants with a family-based network prior to the stroke remained in this network type post stroke. Both before and after the stroke, family were the core of their network (*'My children are everything to me'*, Edward, aged 58). Although there were changes within the family unit (e.g. a child helping with the shopping; participant more likely to receive than make visits), the network structure remained unchanged, and it was rare to move out of this group. While a frequently observed pattern was that people with a diverse network developed a family-based network post stroke, no-one with a friends-based or restricted network developed a family-based network.

Restricted network types

The restricted-supported network type was a vulnerable structure as it was dependent on one or two people for all functional support needs. Reasons for participants shifting out of this category were the ill-health of the relative and a relationship break-up. For older people, it was perhaps particularly vulnerable as their key supporters were more likely to be older, and therefore more likely to experience ill-health themselves. An example is Ivy, 82 years old and single. She had lived all her life with her sister. She reported that in the last few years *'most of my friends have died.'* She described her sister as *'very kind, and she gave me courage.'* After her stroke, Ivy became housebound and more reliant on her sister. A few months later, her sister was taken ill, and it was unlikely she would be able to return home. As a result Ivy saw only her daily carer.

In terms of the restricted-unsupported network type, prior to the stroke only one participant belonged to this category; more participants developed this network type post stroke. All those classified as having a restricted-unsupported network described symptoms of depression post stroke.

Case example: moving from restricted-supported to restricted-unsupported

Prior to the stroke, *Chris* was working full-time as a manager, and was involved with a number of sporting activities at which he excelled. For emotional support he relied on his partner. His two sons did not live locally. At the age of 58 he had a severe stroke leaving him with severe aphasia (verbal output limited to 'yes', 'no' and swear words) and difficulty walking. His partner left him and he lost contact with the people he knew through work and sport. One year post stroke the only people he saw regularly were his sons (about once a fortnight). He indicated that his life was awful.

Quantitative analysis to develop a social network typology (n=71)

Cluster analysis was also used to develop a network typology, using data from the main study collected six months post stroke (n=71). Hierarchical cluster analysis found that a four cluster solution was optimal (see on-line Appendix C for more detail, including plots of the agglomeration coefficients). Four clusters were therefore requested using *k*-means cluster analysis. The final cluster centres are presented in Table 3. Means approximately half a standard deviation above or below the overall mean for the sample represent defining peaks of the clusters.

insert table 3

All four delineating variables contributed to differentiating between the clusters, as indicated by their significant F values (see on-line Appendix D). The four clusters contained between 9 and 23 participants. The clusters that emerged could be matched to the social network typology developed in the qualitative data. They were characterised as follows:

1. Cluster One: Diverse. Above average Children, Relatives and Friends factors, although below average on the Groups factor.
2. Cluster Two: Friends-based. Above average non-kin (Friends and Groups); below average Children and Relatives factors.
3. Cluster Three: Family-based. Strong in both Children and Relatives factors; non-kin contact below average.
4. Cluster Four: Restricted. Low scores in all domains

There is only one restricted network type revealed. In fact, it would not have been possible to replicate the restricted supported/unsupported distinction as information on which network members provided functional support was not collected and so could not be entered into cluster analysis. The network types found through cluster analysis are represented graphically in Figure 3.

insert figure 3

Discussion

This study developed a social network typology in order to better understand potential alterations to social networks following a stroke. Seventy-one participants were assessed using the Stroke Social Network Scale at two weeks and six months post stroke, and a subset of 29 participants took part in in-depth interviews 8-15 months post stroke. Based on the qualitative material, we developed a typology comprising the following network types: diverse; friends-based; family-based; restricted-supported; and restricted-unsupported. It was possible to assign all 29 participants from the qualitative arm of the project to a network type both before and after the stroke. The most populated network type prior to the stroke was the 'diverse' network (plentiful contact with kin and non-kin); post stroke the family-based

network type was most populated. The main shift that took place was participants moving out of a diverse network into a family-based one, explained by the tendency for people to lose friends but keep in contact with family. Yet despite the general trend for friendship loss, the friends-based network type appeared relatively stable. Another trend was that the restricted-unsupported network type became more populated post stroke. Triangulatory evidence for the validity of the typology was provided by *k*-means cluster analysis. The factors of the Stroke Social Network Scale were used as delineating variables (n=71) to produce clusters (or network 'types') with comparable characteristics to the qualitative typology, providing supporting evidence that the sample can be meaningfully sectored into these broad network groups.

Although the variables used to classify participants were specific to this project, emerging from the qualitative data set, the resulting network types match previous social network typology research. In common with previous literature, we discovered the following network types: diverse, friends-based, family-based, restricted (Fiori et al., 2006; Litwin, 2001; Litwin & Shiovitz-Ezra, 2011; Spencer & Pahl, 2006; Wenger, 1994). We further subdivided the restricted category. Wenger (1994) similarly found her 'private restricted' category could be subcategorised into 'independent married couples' and 'dependent elderly'; likewise Spencer and Pahl (2006) found two restricted categories: 'partner-based' and 'professional based' (i.e. reliance on professionals as no close kin). Our 'restricted-supported' category reflects that in our sample, the close supportive relationship was sometimes a sibling or child rather than a partner.

Cross sectional research has found that those with restricted and family-based networks tend to be older and more disabled (Fiori et al., 2006; Litwin, 2001); and longitudinal studies document frailty and old age (Wenger, 1994) and poor health (Li and Zhang, 2015) as risk factors for moving network type. Our research similarly found that physical disability,

particularly where a person becomes housebound, is an obstacle to maintaining a diverse network. However, other factors also appeared to be important, such as the availability of locally-based friends and local supportive groups, as well as the psychological impact of illness and whether a person felt vulnerable and withdrawn. A longitudinal stroke study found that having few social contacts outside the house was a significant predictor of depression. By three years post stroke 66% of non-depressed participants had met with a friend or relative in the previous week compared to only 7% of depressed participants (Astrom, Adolfsson, & Asplund, 1993).

Friendship loss post stroke is well-documented (Northcott, Moss, et al., 2015), thus it might be anticipated that a friends-based network would be vulnerable to network change post stroke. In fact, this did not happen. It seems likely that this reflects the perceived quality of the friendships, and also that these participants had fewer family resources to fall back on. Labi, Phillips, and Greshman (1980) also documented that those who named a friend rather than a spouse as their significant other, and those who lived alone, were less likely to reduce out-of-house socialising following a mild stroke.

The longitudinal social network study conducted by Wenger (1994) concluded that most network types in fact remain stable over time, with only a small percentage shifting each year. By contrast, over one third of the sample in our qualitative study shifted network types. While the sampling was purposive and prevalence rates need to be interpreted cautiously, still, it is likely that following a stroke network shifts are relatively common. Of interest, people with restricted networks prior to the stroke did not develop a more supportive network type post stroke, despite increased support needs. Similarly, people with a friends-based network did not develop a family-based or diverse network. These patterns suggest that close family ties were not commonly built up following the stroke, but rather, where family provided increased support generally this reflected close family relationships prior to the

stroke. Certainly, the participants who felt closer to their adult children post stroke tended to be those who had high quality relationships with their children 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 (Régnier-Loilier, 2006).

One factor which we anticipated might cause a person to shift network type was aphasia. There is evidence that people with aphasia take part in fewer social activities, are at risk of losing friends, and can feel excluded from social participation (Cruice et al., 2006; Parr, 2007; Vickers, 2010). People with aphasia have been found to have significantly fewer contacts with friends than healthy older adults (Hilari & Northcott, 2016). It is therefore of interest that aphasia did not preclude a person retaining a friends-based network. In common with pre-existing literature (Northcott, Moss, et al., 2015; Parr, 2007), these participants sometimes encountered stigma within their wider social networks, and their aphasia could make conversations more difficult or effortful. Nonetheless, participants who belonged to this network type pre-stroke appeared able to retain their most important friends and so this network type post stroke, despite having aphasia.

We also anticipated that age might be a factor in what network type a person belonged to. The 'old-old' (over 80) tend to maintain fewer elective ties and lose touch with those on the periphery of their networks (Fingerman, 2004). Previous social network typology research has found old age is predictive of belonging to a restricted network type (Li & Zhang, 2015). Survey research (n=26,784) exploring the relationship between old age, mental health and social networks has found that smaller social network structures (number of meaningful contacts) were significantly associated with worse mental health, and that this association was strongest amongst those aged over 80 (Litwin, Stoeckel, & Schwartz, 2015). The authors suggest that this finding 'emphasizes the importance of having a sufficient number of meaningful people with whom to interact in the latest stage of life' (p307). In the present

study, the restricted networks were predominantly made up of those aged over 75 years old: as anticipated, it was common for these participants to describe how friends and family members had died, become disabled or unwell, which, combined with their own frailty or disability, had limited contact. While those in restricted-supported networks benefitted from the emotional closeness of a key supporter, it was a network structure vulnerable to change. Those in the restricted-unsupported networks described poor mental health. There were, however, also participants aged over 75 represented in the diverse and friends-based categories both pre and post stroke.

The social network typology developed through cluster analysis matched the qualitative typology well. The only surprising result was that Cluster One (Diverse) scored below average on the Groups factor. In fact, group membership was not a delineating variable for the qualitative typology, so this result does not contradict the qualitative typology. Nonetheless, it is a surprising finding, as the literature suggests those in diverse networks are typically involved in multiple groups/ community activities (Fiori et al., 2006; Litwin, 2001; Wenger, 1994). This result may reflect the fact that group membership for this sample was low even before the stroke. Thus pre-morbidly, the mean (SD) number of groups that participants belonged to was 0.88 (1.03). Approximately 50% of participants did not belong to any group. Six months post stroke, the mean number of groups had reduced only slightly to 0.79 (1.0). Thus for the majority of participants in this sample group membership was not a key factor in their social network. The only participants for whom group membership appeared to contribute a significant component six months post stroke were those in Cluster Two (‘friends-based’).

Strengths/limitations

A strength of the study was the inclusion of people with aphasia, with interviews being conducted by experienced speech and language therapists. Another strength of the study was

the use of cluster analysis to provide triangulatory evidence as to the validity of the qualitative typology. Nonetheless, it would have provided stronger evidence had the timescales matched (quantitative data collected at six months; qualitative at roughly one year), and the delineating variables been more similar. For example, a key consideration in assigning participants to the qualitative typology was determining how much support they received from different network members: the SSNS does not assess this, and therefore this could not be entered into cluster analysis.

A limitation of the study is the timescale: at one year post stroke, many were anticipating further recovery and as such, their social networks were arguably still in the process of transition. In terms of generalisability this study explores the experiences of those recruited through London teaching hospitals, and may not transfer to other contexts.

Clinical implications

There is broad consensus that health service provision should consider the social consequences of health states (Intercollegiate Stroke Working Party, 2016). It is of concern, therefore, that having a stroke increased the risk of a person developing a restricted social network. In our qualitative typology, 3% belonged to a restricted unsupported-network prior to the stroke: this rose to 17% by six months post stroke. Given the close links between social isolation and other adverse outcomes, such as worse recovery and poorer quality of life (Northcott, Moss, et al., 2015), stroke services should consider how best to support a person in maintaining social contacts or even developing new contacts. This may involve health professionals paying greater attention to a client's social context during the rehabilitation process, and potentially working more closely with social services and the voluntary sector. Preliminary evidence suggests that therapy delivered in a group context, and on-going peer support, may be helpful in alleviating isolation (van der Gaag et al., 2005; Vickers, 2010).

Caution is perhaps necessary, however, before prescribing increased social participation for all who have reduced social networks post stroke. Machielse (2015) argues that the socially isolated are not a homogenous group, and that 'interventions should fit with the ambitions and strategies of the clients involved' (p.350). Their study explored social work interventions, interviewing socially isolated individuals, social workers, and examining log books detailing case studies. For individuals who had been isolated for many years it took time to build trust, and brief 'one size fits all' social interventions were less successful. There is also arguably a need to respect that some participants preferred spending time with close family and friends following the stroke rather than seeking to participate more widely: Machielse (2015) also describes a subset who she termed 'secures' who sought protective 'safe' family environments.

Our research found that it is not only physical disability that causes a person to shift network type, but also the psychological impact of stroke, causing a withdrawal from social interaction. There is arguably a need for further research exploring how best to provide psychological support post stroke in a way that enables people to re-engage socially, for example, through approaches such as solution focused brief therapy (Northcott, Burns, Simpson, & Hilari, 2015).

Another implication from our research is that for those reporting friends-based networks prior to the stroke, friends were their primary source of support rather than family, and this remained true even after the stroke. Other research has found that friends can play a key role in enabling a person to 'live successfully' following stroke and aphasia (Brown, Davidson, Worrall, & Howe, 2013). While there is rightly recognition of the importance of including spouses and primary carers during rehabilitation in stroke guidelines (Intercollegiate Stroke Working Party, 2016), there is less emphasis on considering a person's friendship circle. It may be that supporting friends when they first visit hospital to communicate more

successfully with a person who has aphasia, or considering maintaining friendships as a legitimate goal of therapy, would be valuable.

Conclusion/summary

We interviewed people two weeks, six months and one year post stroke in order to develop a social network typology and explore patterns of social network change post stroke. Around one third of participants shifted from one social network 'type' to another post stroke, most commonly from a 'diverse' network (plentiful contact with both family and friends) to a family-based network. The friends-based network appeared relatively stable. More people belonged to restricted network types following the stroke. Triangulatory evidence for the validity of the typology was provided by *k*-means cluster analysis. Stroke services should consider the social impact of stroke, and how best to support those in restricted network types.

Adamson, J., Beswick, A., & Ebrahim, S. (2004). Is stroke the most common cause of disability? *J Stroke Cerebrovasc Dis, 13*(4), 171-177. doi: 10.1016/j.jstrokecerebrovasdis.2004.06.003

Astrom, M., Adolfsson, R., & Asplund, K. (1993). Major depression in stroke patients. A 3-year longitudinal study. *Stroke, 24*(7), 976-982. doi.org/10.1161/01.str.24.7.976

Brown, K., Davidson, B., Worrall, L. E., & Howe, T. (2013). "Making a good time": the role of friendship in living successfully with aphasia. *Int J Speech Lang Pathol, 15*(2), 165-175. doi: 10.3109/17549507.2012.692814

Burns, R. P., & Burns, R. (2008). *Business Research Methods and Statistics Using SPSS*. London: Sage.

Carstensen, L. L., Isaacowitz, D. M., & Charles, S. T. (1999). Taking time seriously. A theory of socioemotional selectivity. *Am Psychol, 54*(3), 165-181. doi.org/10.1037//0003-066x.54.3.165

Cruice, M., Worrall, L., & Hickson, L. (2006). Quantifying aphasic people's social lives in the context of non-aphasic peers. *Aphasiology, 17*(4), 333-353. doi.org/10.1080/02687030600790136

Enderby, P. M., Wood, V. A., Wade, D. T., & Hewer, R. L. (1987). The Frenchay Aphasia Screening Test: a short, simple test for aphasia appropriate for non-specialists. *Int Rehabil Med, 8*(4), 166-170. doi.org/10.3109/03790798709166209

Fingerman, K. L. (2004). The consequential stranger: Peripheral relationships across the life span. In F. R. Lang & K. L. Fingerman (Eds.), *Growing together: Personal relationships across the life span* (pp. 183-209). New York: Cambridge University Press.

Fiori, K. L., Antonucci, T. C., & Cortina, K. S. (2006). Social network typologies and mental health among older adults. *J Gerontol B Psychol Sci Soc Sci, 61*(1), P25-32. doi.org/10.1093/geronb/61.1.p25

Fotiadou, D., Northcott, S., Chatzidaki, A., & Hilari, K. (2014). Aphasia blog talk: How does stroke and aphasia affect a person's social relationships? *Aphasiology, 28*(11), 1281–1300. doi.org/10.1080/02687038.2014.928664

Hair, J. H., & Black, W. C. (2000). Cluster analysis. In L. G. Grimm & P. R. Yarnold (Eds.), *Reading and understanding more multivariate statistics* (pp. 147-205). Washington, DC: American Pyschological Association.

Hilari, K., Lamping, D. L., Smith, S. C., Northcott, S., Lamb, A., & Marshall, J. (2009). Psychometric properties of the Stroke and Aphasia Quality of Life Scale (SAQOL-39) in a generic stroke population. *Clin Rehabil, 23*(6), 544-557. doi: 10.1177/0269215508101729

Hilari, K., & Northcott, S. (2016). “Struggling to stay connected”: comparing the social relationships of healthy older people and people with stroke and aphasia. *Aphasiology*. doi: doi.org/10.1080/02687038.2016.1218436

Holt-Lunstad, J., & Smith, T. (2012). Social relationships and mortality. *Social and personality psychology, 6*(1), 41-53. doi.org/10.1111/j.1751-9004.2011.00406.x

Intercollegiate Stroke Working Party. (2016). *National clinical guideline for stroke*. London: Royal College of Physicians.

Labi, M. L., Phillips, T. F., & Greshman, G. E. (1980). Psychosocial disability in physically restored long-term stroke survivors. *Arch Phys Med Rehabil, 61*(12), 561-565.

Li, T., & Zhang, Y. (2015). Social network types and the health of older adults: exploring reciprocal associations. *Soc Sci Med, 130*, 59-68. doi: 10.1016/j.socscimed.2015.02.007

Litwin, H. (2001). Social network type and morale in old age. *Gerontologist, 41*(4), 516-524. doi.org/10.1093/geront/41.4.516

Litwin, H., & Shiovitz-Ezra, S. (2011). Social network type and subjective well-being in a national sample of older Americans. *Gerontologist, 51*(3), 379-388. doi: 10.1093/geront/gnq094

Litwin, H., Stoeckel, K. J., & Schwartz, E. (2015). Social networks and mental health among older Europeans: are there age effects? *European Journal of Ageing, 12*(4), 299-309. doi.org/10.1007/s10433-015-0347-y

Machielse, A. (2015). The heterogeneity of socially isolated older adults: a social isolation typology. *J Gerontol Soc Work, 58*(4), 338-356. doi: 10.1080/01634372.2015.1007258

Northcott, S., Burns, K., Simpson, A., & Hilari, K. (2015). 'Living with aphasia the best way I can': A feasibility study exploring Solution-Focused Brief Therapy for people with aphasia. *Folia Phoniatr Logop, 67*(3), 156-167. doi: 10.1159/000439217

Northcott, S., & Hilari, K. (2011). Why do people lose their friends after a stroke? *Int J Lang Commun Disord, 46*(5), 524-534. doi: 10.1111/j.1460-6984.2011.00079.x

Northcott, S., & Hilari, K. (2013). Stroke Social Network Scale: development and psychometric evaluation of a new patient-reported measure. *Clin Rehabil, 27*(9), 823-833. doi: 10.1177/0269215513479388

Northcott, S., Moss, B., Harrison, K., & Hilari, K. (2015). A systematic review of the impact of stroke on social support and social networks: Associated factors and patterns of change. *Clin Rehabil*. doi: 10.1177/0269215515602136

Parr, S. (2007). Living with severe aphasia: tracking social exclusion. *Aphasiology, 21*(1), 98-123. doi.org/10.1080/02687030600798337

Pinquart, M., & Sorensen, S. (2000). Influences of socioeconomic status, social network, and competence on subjective well-being in later life: a meta-analysis. *Psychol Aging, 15*(2), 187-224. doi.org/10.1037//0882-7974.15.2.187

Régnier-Loilier, A. (2006). How often do adult children see their parents? *Population and Societies, 427*, 2-5.

Ritchie, J., Lewis, J., & Elam, G. (2003). Designing and selecting samples. In J. Ritchie & J. Lewis (Eds.), *Qualitative research practice: a guide for social science students and researchers*. London: Sage.

Ritchie, J., & Spencer, L. (1994). Qualitative data analysis for applied policy research. In A. Bryman & R. Burgess (Eds.), *Analysing qualitative data*. London: Routledge.

Singleton Jr, R. A., Straits, B. C., & Straits, M. M. (1993). *Approaches to social research*: Oxford University Press.

Spencer, L., & Pahl, R. (2006). *Rethinking friendship: hidden solidarities today.* New Jersery: Princeton University Press.

Spencer, L., Ritchie, J., O'Connor, W., Morrell, G., & Ormston, R. (2014). Analysis in Practice. In J. Ritchie, J. Lewis, C. McNaughton Nicholls & R. Ormston (Eds.), *Qualitative Research Practice: A Guide for Social Science Students and Researchers* (2nd ed.). London: Sage.

Teo, A. R., Choi, H., & Valenstein, M. (2013). Social relationships and depression: ten-year follow-up from a nationally representative study. *PLoS One, 8*(4), e62396. doi: 10.1371/journal.pone.0062396

van der Gaag, A., Smith, L., Davis, S., Moss, B., Cornelius, V., Laing, S., & Mowles, C. (2005). Therapy and support services for people with long-term stroke and aphasia and their relatives: a six-month follow-up study. *Clin Rehabil, 19*(4), 372-380. doi.org/10.1191/0269215505cr785oa

Vickers, C. (2010). Social networks after the onset of aphasia: the impact of aphasia group attendance. *Aphasiology, 24*(6-8), 902-913. doi.org/10.1080/02687030903438532

Wenger, G. C. (1994). *Support networks of older people: A guide for practitioners*. Bangor: Centre for Social Policy Research and Development, University of Wales.

Winkler, M., Bedford, V., Northcott, S., & Hilari, K. (2014). Aphasia blog talk: How does stroke and aphasia affect the carer and their relationship with the person with aphasia? . *Aphasiology, 28*(11), 1301-1319. doi.org/10.1080/02687038.2014.928665

Table 1. Participant characteristics

Variable	Respondent *n*(%)	
	6 months	8-15 months
	n=71	n=29
Gender		
Female	31(44%)	12 (41%)
Male	40 (56%)	17 (59%)
Age		
Mean (SD)	69.3 (14.1)	68.0 (14.0)
Range	18–91	18–90
Ethnic group		
Asian	9 (13%)	2 (7%)
Black	5 (7%)	6 (21%)
White British	52 (73%)	15 (51%)
White non-British	5 (7%)	6 (21%)
Marital status		
Married/ has partner	38 (54%)	16 (55%)
Single, divorced or widowed	33 (46%)	13 (45%)
Living arrangements		
Living alone/ in hospital or institution	32 (45%)	11 (38%)
Living at home with someone	39 (55%)	18 (62%)
Employment status*		
Not employed	60 (86%)	25 (86%)
Working part time/ voluntary work	4 (6%)	2 (7%)
Working full time/ full time education	6 (8 %)	2 (7%)
Stroke type		
Ischaemic	62 (87%)	21 (72%)
Haemorrhagic	9 (13%)	8 (28%)
Communication disability		
None	58 (82%)	18 (62%)
Dysarthria	2 (3%)	1 (3%)
Aphasia	11 (15%)	10 (35%)

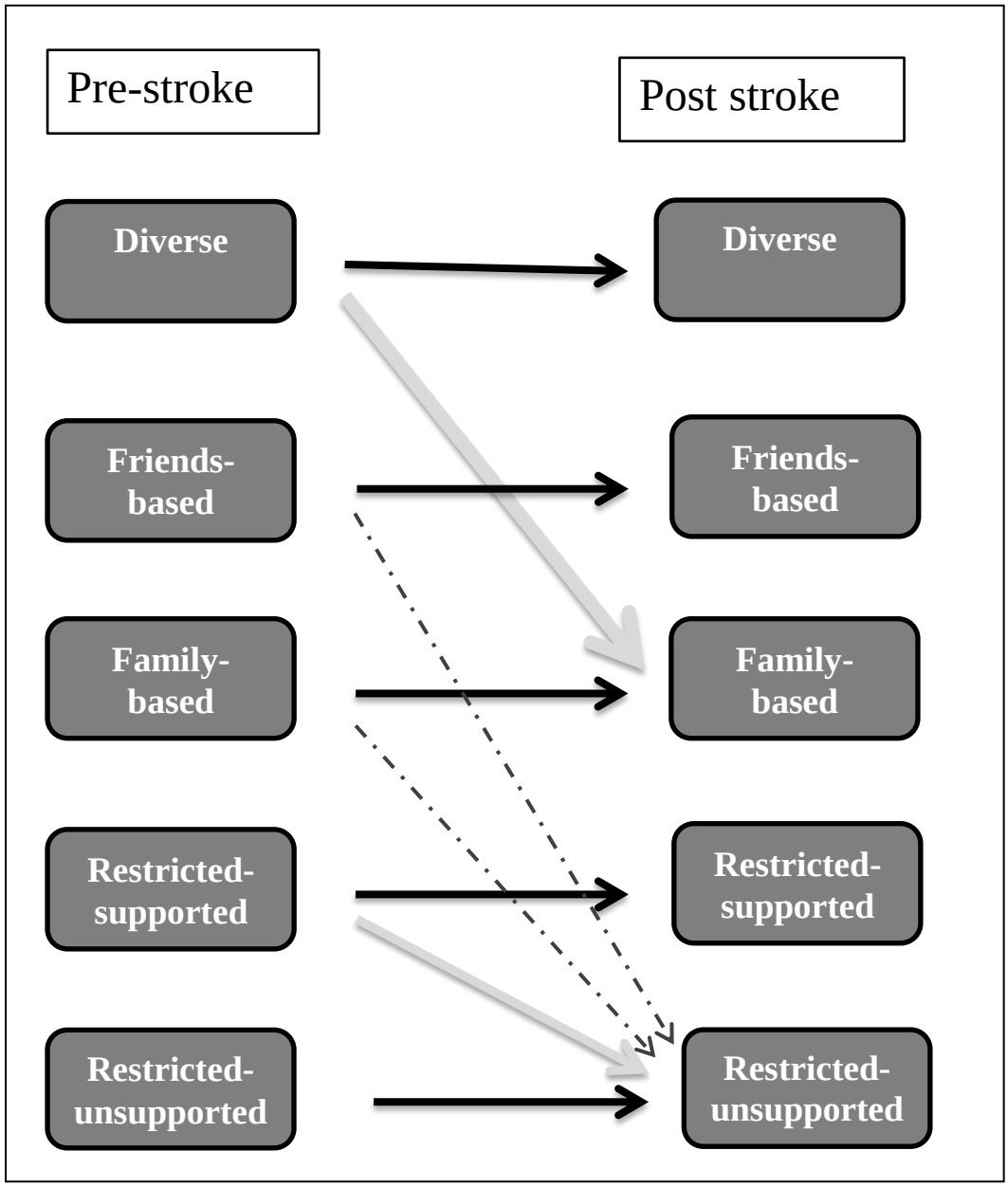
*missing data for n=1 at 6 month data point for employment status

Table 2. Stroke Social Network Scale: descriptive statistics

	Baseline* *n = 87*	**6 months** *n = 71*
Overall score		
Mean (SD)	60.7 (15.2)	56.8 (15.4)
Range	11.3 – 91.7	10.3 – 85.1
Satisfaction		
Mean (SD)	85.2 (15.6)	82.6 (19.2)
Median (IQR)	88.3 (78.3 – 96.7)	86.7 (80.0– 93.3)
Range	35.8 – 100	6.7 – 100
Children		
Mean (SD)	57.6 (35.5)	58.8 (34.2)
Range	0 – 100	0 – 100
Relatives		
Mean	37.8 (28.5)	36.8 (29.2)
Range	0 – 88.9	0 – 93.3
Friends		
Mean (SD)	57.0 (25.0)	44.0 (28.1)
Range	0 – 95	0 – 95
Groups		
Mean (SD)	35.1 (37.1)	31.0 (34.2)
Range	0 – 100	0 – 100

*collected two weeks post stroke, questions relate to the month prior to the stroke

Figure 1: Patterns of change in social network type



Key

= social network type

= no change

= change

= less common pattern of change

Figure 2 Network type of all participants (n=29) before and after stroke

Pre-stroke	Diverse (n=13)	**n=5** Judy (76yrs; A) Cormac (75yrs; S) Winnifred (65yrs; S) Pablo*(63yrs; F) Brian (57yrs; S)		**n=8** Rose (90yrs; S) Gordon (74yrs; S) Martin (68yrs; F) Tomasz (66yrs; F) Peter (65yrs; S) Daren (65yrs; S) Raymond*(63yrs; S) Pratik (18yrs; F)		
	Friends-based (n=7)		**n=6** Gerta (83yrs; A) John (76yrs; A) Leonisa*(74yrs; A) Andy*(69yrs; S) Patricia*(62yrs; F) Steve*(48yrs; A)			**n=1** Bridget (74yrs; A)
	Family-based (n=4)			**n=3** Adebomi*(68yrs; SH) Dolores*(66yrs; NH) Edward (58yrs; F)		**n=1** Hakim*(65yrs; S)
	Restricted-supported (n=4)				**n=2** Dorothy (86yrs; A) Susan (78yrs; S)	**n=2** Ivy (82yrs; A) Chris*(58yrs; SH)
	Restricted-unsupported (n=1)					**n=1** Paul (76yrs; SH)
		Diverse (n=5)	Friends-based (n=6)	Family-based (n=11)	Restricted-supported (n=2)	Restricted-unsupported (n=5)
	Post-stroke					

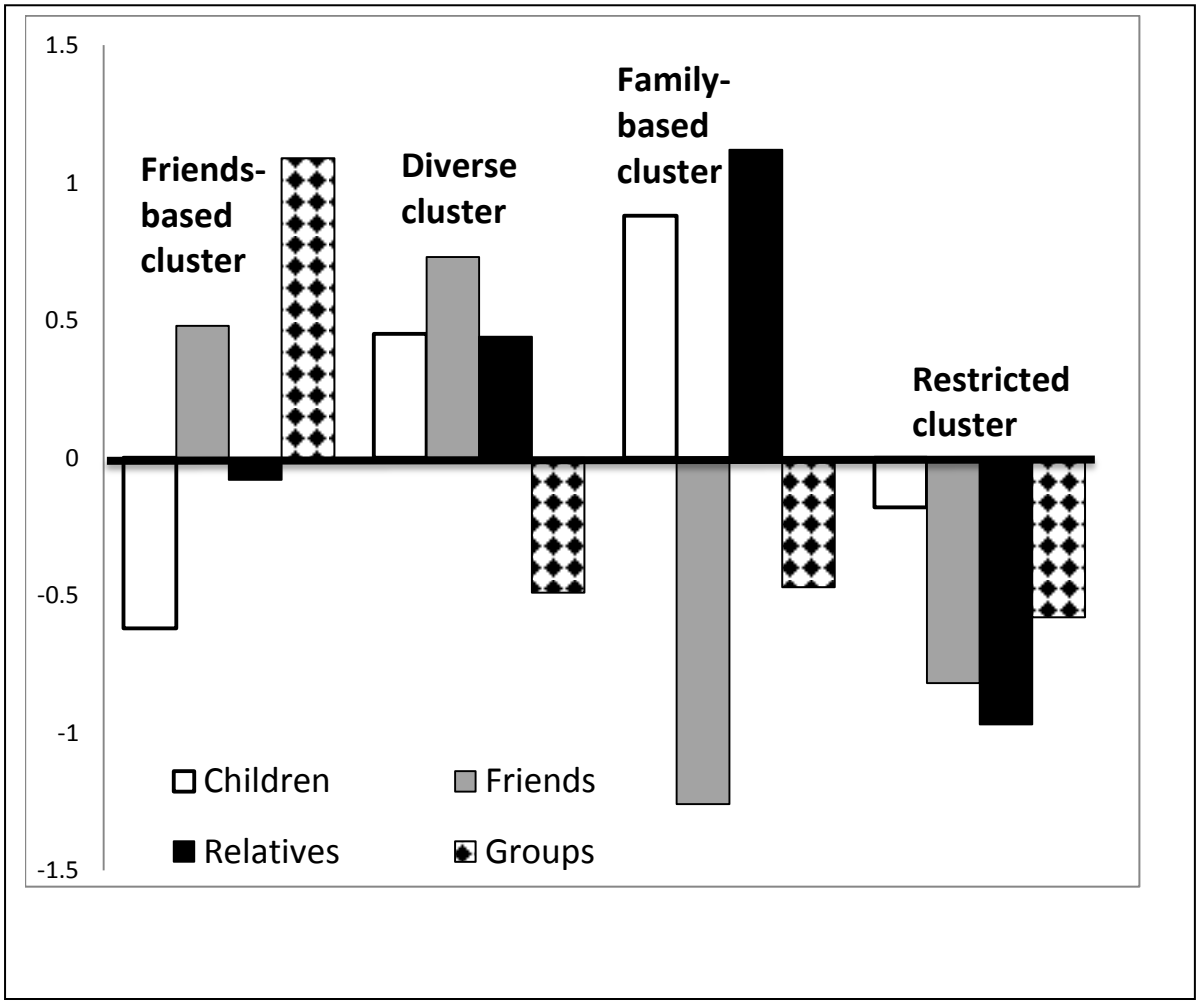
Key: Communication disability: * = aphasia
Living situation post stroke: A = living alone; S = living with spouse; F = living with family members; SH = living in sheltered housing; NH = living in nursing home
Note: all names fictional

Table 3: Factor means for the different clusters

	Delineating characteristics				
Network type	Children factor	Friends factor	Relatives factor	Groups factor	Frequency (%)
Diverse	.45	**.73**	.44	-.49	*n*=21 (30%)
Friends-based	**-.62**	.48	-.08	**1.09**	*n*=23 (32%)
Family-based	**.88**	**-1.26**	**1.12**	-.47	*n*=9 (13%)
Restricted	-.18	**-.82**	**-.97**	**-.58**	*n*=18 (25%)

Key: numbers in bold represent means approximately half a standard deviation above or below overall mean for the sample, and thus define the character of each cluster.

Figure 3: Mean scores of the social network factors by cluster type



On-line Appendix A. Selecting participants for qualitative interviews: methods

Only a subset of participants from the main study, exploring quality of life and social relationships, took part in qualitative interviews. Deciding who to include in the qualitative arm of the project was determined by pre-set selection criteria. These selection criteria were used to create a sampling matrix. The purpose of the matrix was to ensure that participants represented different experiences of social support, and that the process was systematic.

As participants became eligible for qualitative follow up (i.e. at least eight months post stroke), their characteristics were checked against the matrix. The aim was that each cell in the matrix should include between one and three participants. Potential participants were therefore contacted if they fulfilled the requirements to fit into a vacant or underpopulated cell in the sampling matrix, with further consideration given to secondary selection criteria. Those with aphasia and the youngest stroke survivors were preferentially included to ensure they were adequately represented.

Primary criteria used to create matrix

Perceived social support, as measured by the MOS Social Support Survey six months post stroke (Sherbourne & Stewart, 1991): participants were grouped according to whether they scored in the top, middle or bottom third of the sample population. This assessment measures the perceived availability of different support functions, such as emotional, practical, informational, and affectionate support and social companionship.

Aphasia. Presence of aphasia was determined using Frenchay Aphasia Screening Test (Enderby et al., 1987), with the exception of one participant who scored in the 'normal' range

but where both clinical judgement and participant perception indicated mild expressive aphasia.

Severity of stroke. Stroke severity was measured using the National Institute of Health Stroke Scale (NIHSS) (Brott et al., 1989) at two weeks post stroke. Participants were divided into mild stroke (≤5), moderate stroke (6-10) and moderate to severe (11+). The cut-off points were derived from studies examining the predictive validity of the NIHSS (Meyer, Hemmen, Jackson, & Lyden, 2002; Schlegel et al., 2003).

Age. The two main categories were over 65 (i.e. likely to be retired), and 65 or under. Furthermore, targets were set to ensure that the oldest old (over 80) and youngest stroke survivors (under 50) were also included, so that a range of ages were represented.

Secondary criteria

In addition to the primary selection criteria outlined above some further criteria were set. These were:

Additional social support factors. These included the size of network, number of close friends, whether living alone and marital status (data collected at six months post stroke). Specific targets were set, for example, recruiting at least two people with no friends; and at least two people who lived alone but also perceived their support to be good.

Gender and ethnicity. The number of men and women, and the ethnicity of the sample was monitored to ensure it mirrored the larger stroke sample.

Participants recruited

The figure below shows how the 29 participants recruited fitted into the sampling matrix.

On-line Appendix A Figure: 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** was measured using the MOS Social Support Survey six months post stroke (Sherbourne and Stewart, 1991); **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.

Brott, T., Adams, H. P., Jr., Olinger, C. P., Marler, J. R., Barsan, W. G., Biller, J., . . . et al. (1989). Measurements of acute cerebral infarction: a clinical examination scale. *Stroke, 20*(7), 864-870.

Enderby, P. M., Wood, V. A., Wade, D. T., & Hewer, R. L. (1987). The Frenchay Aphasia Screening Test: a short, simple test for aphasia appropriate for non-specialists. *Int Rehabil Med, 8*(4), 166-170.

Meyer, B. C., Hemmen, T. M., Jackson, C. M., & Lyden, P. D. (2002). Modified National Institutes of Health Stroke Scale for use in stroke clinical trials: prospective reliability and validity. *Stroke, 33*(5), 1261-1266.

Schlegel, D., Kolb, S. J., Luciano, J. M., Tovar, J. M., Cucchiara, B. L., Liebeskind, D. S., & Kasner, S. E. (2003). Utility of the NIH Stroke Scale as a predictor of hospital disposition. *Stroke, 34*(1), 134-137.

Sherbourne, C. D., & Stewart, A. L. (1991). The MOS social support survey. *Soc Sci Med, 32*(6), 705-714.

On-line Appendix B. Topic guide for qualitative interviews

Social support after a stroke: topic guide

1. Present Circumstances

- When had the stroke
- Length of stay in hospital/ post hospital health care support
- Living situation
- Group memberships
- Family structure

2. Current social contacts

I'd like now to get a picture of your life, and find out who you see and what you do with them

2.1. Over last week

So over this last week, can you remember

Researcher to map out social contacts mentioned

- Who seen
- Telephone, email, letter contact (what about people you spoke to over the telephone…)

2.2 Discussion about each social contact

['So you said you saw X, can you tell me a little bit more about what you did together?']

- What they did together/ where
- What talked about
- How arranged (prearranged, who initiated contact)
- Regularity/ frequency of contact

2.3 Checks

- How typical - check week described was typical. In what way was it not typical? What would be more typical? Anybody you normally see that you haven't seen?
- Important relationships not mentioned

Checklist of contacts:

1) Partner
2) Children
3) Other relatives
4) Friends
5) Groups
6) Neighbours
7) Acquaintances
8) Other (eg professionals, shopkeepers, volunteers)

3. Changes since stroke

'I'd like to think now a little about your life before the stroke.'

3.1 Changes to typical week

- In terms of week just described – the same as before the stroke? Ways in which different?
- Missing people: Who seen – any people now missing? 'Are there people you used to see, but don't see any longer?'
- People still seen: any changes?

- Frequency
- Where seen
- How arranged/initiated
- What they do/activities
- What talked about

(Reflections on change incl. causes for change)

Prompts: 'other people have mentioned various things which they feel have changed how much they want to see others':

- Energy levels
- Mobility
- Feeling 'down'

Possible issues:		
1) Reciprocity	4) Ability to share activities/experiences	7) Depression
2) Expectations (extent met)	5) Ability to travel after the stroke	8) Disability
3) **Points of anxiety/conflict**	6) Increased support needs	9) Pain

4. Importance of members in network

4.1 **Friends** - General

What has happened to friendships since the stroke
Role of friends post stroke.
Protective factors in maintaining friendships

4.1.2 The 'good' friend

- Name (eg 'Think of a really good friend' Someone you feel is particularly important to you/you feel particularly close to)
- Description of a 'friendly' act (eg 'Tell me about a particular time or occasion or conversation, that illustrates why they are a good friend')
- Attributes of a good friend (eg 'What makes them a good friend?')
- Changes since the stroke (and reasons for changes)

4.1.3 The 'lost' friend

- Name (eg 'Now think of a friend that you feel less close to after the stroke')
- Reasons for estrangement (eg 'Why do you think you have become less close?')
- Meaning attached to this (eg 'How do you feel about this?')

4.2. Family

4.2.1. General:

What has happened to your relationships with your family since stroke?
Role of family post stroke

- Close family member: Family member they feel close to. What makes them feel close?
- Family member less close to since the stroke.

4.3 Friends versus family

- What friends versus family 'give' them
- Role of friends versus family in adjusting to life after a stroke
- Expectations of friends versus family (what friends provide that family don't and vice versa)

4.4. Wider social network

Discussion about role of wider social network, acquaintances etc post stroke.

5. Types of support

Now various people have written about social support. Various types. Run them past you to

get your thoughts on them.

- Source (eg Who gives them this type of support; Who do they get X support from?)
- Role in adjusting to stroke (eg has this kind of support been helpful since the stroke? what role do they feel this kind of support has had since their stroke)
- Meaning (eg What does this kind of support mean to them?)
- Sufficiency (eg do they feel they have amount of support they need? Do they get enough of it?
- Temporal – was there a particular time since the stroke when this type of support was particularly important to you?

Definitions of different types of support

1. Emotional support
(feeling there is someone you can confide in and talk to about what's worrying you, feeling that there is someone who will understand and will listen sympathetically)
2. Practical support
(feeling that there is someone who can help with practical things, for example, if you were feeling unwell, they could help with daily chores, or get your shopping)
3. Social companionship
(feeling that there is someone you can relax with, that seeing them will take your mind off things, that you can have a good time together)
4. Informational support
(feeling there is someone who will give you advice or useful information)
5. Any other types?
(eg. 'Are there any other types of support that I haven't mentioned, but that you feel are important?')

6. Support not received/ unhelpful support

- Support not received. (Any sort of support that you didn't receive that would have been helpful?)
- Unhelpful support. (Any kind of support that you found unhelpful? Eg unwanted advice, unwanted practical support)

7. Suggestions/learning from their experience

Sign post coming to end of interview

7.1 Advice

- To someone who's just had a stroke (in terms of social support)
- To the friends and relatives of someone who's just had a stroke

7.2 Further comments

- Eg Anything else about friends, family, your social network, that we haven't mentioned today, but which they feel is important?

- What would you say really helped in terms of support from family and friends after the stroke?

Provision of any relevant information (eg local or national services) Reassurances about confidentiality, what will happen next Thank yous

On-line Appendix C. Cluster Analysis: methodology

Cluster analysis is an exploratory data analysis tool, which organises data (in this project, participants) into clusters or 'groups' (Burns & Burns, 2008). An aim was to select variables to be entered into cluster analysis that matched the delineating variables used to define the qualitative typology. Four of the five factors that make up the Stroke Social Network Scale (SSNS) (Northcott & Hilari, 2013) were selected: Children, Friends, Relatives and Groups. The SSNS includes items on frequency of face to face and remote contact, number of contacts, and proximity. A decision was taken not to include the measure of perceived functional social support, MOS Social Support Survey (Sherbourne & Stewart, 1991) in cluster analysis, as this measure does not differentiate which network members are providing the support. Functional social support was only a delineating variable in the qualitative typology in so far as it helped to differentiate the role of network members.

Since the variables used (social network factors) did not all have the same variance, they were standardised prior to entry into cluster analysis (Field, 2000; Hair & Black, 2000). Hierarchical cluster analysis was used initially to determine the optimum number of clusters (Burns & Burns, 2008). Having determined the number of clusters, *k*-means clustering was used. These cluster analysis techniques are now described in more detail.

Hierarchical cluster analysis

Hierarchical cluster analysis makes no assumptions about the number of clusters that will be created. Each case (participant) starts as a separate cluster. They are then combined sequentially, thus at each step the number of clusters is reduced until there is only one cluster left. The way in which clusters are combined is based on maximising the similarity between cases within each cluster, while minimising the similarity between groups. In terms of measuring the distance between cases, squared Euclidean distance was used. Euclidean

distance is the geometric distance between two cases (Field, 2000): the smaller the Euclidean distance, the more similar the cases. Euclidean distance is only suitable for continuous variables, which is the case in this study (Norušis, 2008).

As the process of fusing cases proceeds, increasingly dissimilar cases will be joined. The process should be halted, therefore, at a point where the clusters are meaningful and participants have been grouped in a useful way. In the present project, the optimal number of clusters was determined by examining the agglomeration schedule. This gives information on the similarity (or distance) statistic used to create a cluster. The optimal number of clusters was defined by where there was a sharp jump in the size of adjacent coefficients (i.e. the measure of similarity or dissimilarity), determined through inspection of the plot of the agglomeration coefficients against the number of clusters formed (Norušis, 2008).

There are different methods of conducting hierarchical cluster analysis, which use different criteria for merging clusters. Thus different solutions may be produced for the same data, depending on which method has been chosen (Field, 2000; Norušis, 2008). In order to find the optimal number of groups for the current data set, three different methods were employed and results compared in order to improve the validity of the results. The methods were: Between Groups, Furthest Neighbour and Ward's method. In Furthest Neighbour, the initial cluster is between the two most similar cases. These are then fused with the case that has the highest similarity score to both the original two cases. With Between Groups, the initial cluster is the same as for the Furthest Neighbour. However, the next case to be fused will be the case that is most similar to the average similarity of the initial cluster. In Ward's method, cases are joined into clusters such that the variance within a cluster is minimised.

k-means cluster analysis

Having determined the optimal number of groups, *k*-means cluster analysis was employed to allocate participants to clusters. *k*-means clustering produces the number of clusters requested which are 'of the greatest possible distinction.'(Burns & Burns, 2008) At the start of the process, SPSS finds *k* cases that are well-separated, to be used as initial cluster centres. Cases are then assigned to a cluster, determined by their distance from those means. Cluster means are recalculated based on the assigned cases. Cases are then reclassified based on the new set of means. This process is repeated until the cluster means change little between successive steps. Finally, cases are assigned to their permanent cluster. Thus, the algorithm repeatedly assigns cases to clusters, and a case could move from cluster to cluster during the process (Norušis, 2008).

In terms of interpreting results, the characteristics of the clusters are reported. The means of each variable (i.e. social network factor) for the different clusters are presented. ANOVA is used to assess how distinct the clusters are: the size of the F value for each variable gives an indication as to how well it discriminates between clusters.

Burns, R. P., & Burns, R. (2008). *Business Research Methods and Statistics Using SPSS*. London: Sage.

Field, A. (2000). Postgraduate Statistics: Cluster Analysis

Hair, J. H., & Black, W. C. (2000). Cluster analysis. In L. G. Grimm & P. R. Yarnold (Eds.), *Reading and understanding more multivariate statistics* (pp. 147-205). Washington, DC: American Pyschological Association.

Northcott, S., & Hilari, K. (2013). Stroke Social Network Scale: development and psychometric evaluation of a new patient-reported measure. *Clin Rehabil, 27*(9), 823-833. doi: 10.1177/0269215513479388

Norušis, M. J. (2008). *SPSS 16.0 Statistical Procedures Companion*. Upper Saddle River, NJ: Prentice Hall.

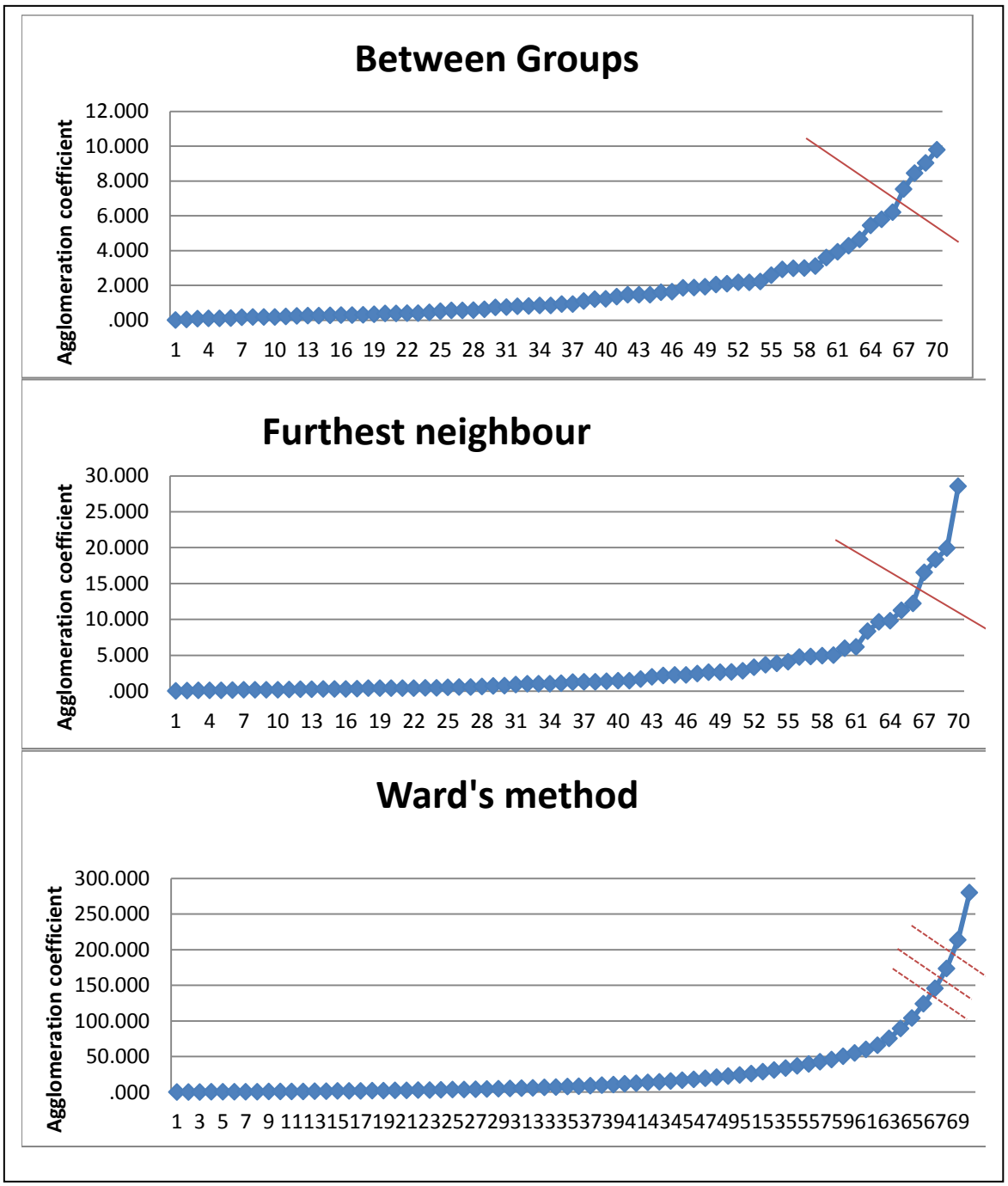
Sherbourne, C. D., & Stewart, A. L. (1991). The MOS social support survey. *Soc Sci Med, 32*(6), 705-714.

On-line Appendix D. Cluster Analysis: Results

Initially hierarchical cluster analysis was carried out, using the following three techniques for combining clusters: Between Groups, Furthest Neighbour and Ward's method. The plots of the agglomeration coefficients against the number of clusters formed are presented below in Appendix D Figure 1 for each method used. As can be seen from the plots, the first cluster formed in the clustering process contains cases very similar to one another (hence the low agglomeration coefficient). As the clustering process continues, cases that are more dissimilar start to be combined (hence the observed pattern that the agglomeration coefficients become larger). Where there is a sharp increase between adjacent coefficients, it suggests that to combine cases further would result in clusters made up of very dissimilar cases. With both Between Groups and Furthest Neighbour there is a relatively large increase in the coefficient values between the fourth and fifth steps, suggesting that a four cluster solution is preferable. For the Ward's method, the plot is more ambiguous, with potentially a two, three or four cluster solution all equally possible.

From this evidence, a four cluster solution appeared most valid, and therefore four clusters were requested, using *k*-means clustering. As discussed in the methods section, the social network factors were standardised prior to entry into cluster analysis, so that they all contributed equally to the distance or similarity between cases. They thus have a mean of 0, and standard deviation of 1. All four delineating variables contributed to differentiating between the clusters, as indicated by their significant F values. ANOVAs are reported in full in Appendix D Figure 2 below.

Appendix C Figure 1. Plots of the agglomeration coefficients against the number of clusters formed: three methods of hierarchical cluster analysis



Appendix D, Figure 2. *k*-means cluster analysis: ANOVA

ANOVA

	Cluster		Error		F	Sig.
	Mean Square	df	Mean Square	df		
Zscore: Children Factor	6.902	3	.736	67	9.380	.000
Zscore: Friends Factor	14.323	3	.403	67	35.503	.000
Zscore: Relatives Factor	10.812	3	.561	67	19.283	.000
Zscore: Groups Factor	13.410	3	.444	67	30.180	.000

The F tests should be used only for descriptive purposes because the clusters have been chosen to maximize the differences among cases in different clusters. The observed significance levels are not corrected for this and thus cannot be interpreted as tests of the hypothesis that the cluster means are equal.