

Hilari, K. & Northcott, S. (2006). Social support in people with chronic aphasia. *Aphasiology*, 20(1), 17 - 36. doi: 10.1080/02687030500279982 <<http://dx.doi.org/10.1080/02687030500279982>>



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**Original citation:** Hilari, K. & Northcott, S. (2006). Social support in people with chronic aphasia. *Aphasiology*, 20(1), 17 - 36. doi: 10.1080/02687030500279982 <<http://dx.doi.org/10.1080/02687030500279982>>

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## **Social support in people with chronic aphasia**

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### **Acknowledgements**

We are grateful to all the respondents and their families for participating in this study and to the Speech and Language Therapists in the recruiting sites for their help. We would also like to thank Prof Jane Marshall for her helpful comments in reviewing an earlier version of this paper. Thanks are also due to the funders of this research: the Stroke Association and the Dunhill Medical Trust.

### Abstract

*Background and aims:* Stroke and aphasia can have a profound impact on people's social activities, family and social relationships. This study looked at patterns of social support in people with chronic aphasia following stroke. It examined the relationship between social support and quality of life, exploring which aspects of social support (social network versus perceived social support) were most associated with health-related quality of life (HRQL).

*Methods:* A cross-sectional interview based survey study was conducted. A cluster sampling framework was used to recruit participants with chronic aphasia following stroke (> 1 year) from three different sites in the South-East of England. Measures included the Stroke and Aphasia Quality of Life Scale- 39 item version (SAQOL-39), the MOS Social Support Survey (SSS) and a social network questionnaire. Descriptive statistics, correlation, t-tests and ANOVAs were used as appropriate.

*Results:* The results of those able to self-report (83 out of 95 participants, 87%) are reported here. In terms of social networks, the mode of the size of network was 4. Size of network was associated with HRQL for women only. Most participants (71%) reported they had the same amount of contact with their children following the stroke, while 64% reported they saw their friends less. Those who had the same level of contact with their family as before the stroke had the highest HRQL scores; those who saw them either less or more than before the stroke had lower HRQL. In terms of perceived social support, the SSS scores were positively skewed with a mean (SD) of 3.69 (.95), suggesting that participants felt overall well supported. Two types of support were significantly correlated with HRQL: social companionship and informational support.

*Clinical implications:* Therapy services for people with aphasia could consider ways to enhance social companionship and informational support as this may positively impact on HRQL. Implications could include complementing and supporting existing social networks, and facilitating access to information and social participation.

(319 words)

**Keywords:** stroke, aphasia, social support, social networks, health-related quality of life.

## INTRODUCTION

### **Social support: Structure and function**

Social support and the links between individuals and the society they live in have long been of interest to sociologists, anthropologists and psychologists. Potentially, the nature of someone's social ties can contribute to explaining behaviour. Over 100 years ago, Durkheim (1879, trans 1952) argued that even an apparently 'individual' act such as suicide could be explained sociologically. He found that suicide rates were lower in societies where individuals were more embedded or integrated into the social groups around them. Thus the individual is influenced by the quality and quantity of their social relationships. Following in this tradition, numerous studies have since found that people with strong social relations have lower morbidity and mortality (Berkman and Syme, 1979; House, Robbins & Metzner, 1982; Blazer, 1982; Broadhead, Kaplan, James, Wagner, Schoenbach, Grimson et al., 1982; Orth-Gomer & Johnson, 1987; Olsen, 1993), better possibility of recovery or survival after illness (Ruberman, Weinblatt, Goldberg & Chaudhary, 1984; Waxler-Morrisson, Hislop, Mears & Kan, 1991; Glass & Maddox, 1992; Vogt, Mullooly, Ernst, Pope & Hollis, 1992) and better psychological health, well-being and quality of life (Aneshensel & Frerichs, 1982; Billings & Moos, 1982; Turner, 1981).

Still, there is a lack of consensus in conceptualising social support. This paper examines social support in terms of its *structure* and *function*, as described by Cohen and Wills (1985). Social network is seen as the structural element. Bowling (1997, p. 90) describes social network as 'the web of identified social relationships that surround an individual and the characteristics of those linkages'. Thus each individual is seen as a node in the network, with each exchange between network members constituting a link. Characteristics of a network can include size of network, frequency of contact, geographic dispersion, density (how much network members are in each other's networks) and composition of members (for example, whether the members are friends, neighbours, children, other relatives etc). Cohen and Wills (1985) suggest the role of a social network is to provide a sense of social integration, a set of stable, socially rewarded roles, as well as stability and predictability.

With functional social support, the emphasis is on a person's subjective experience of support and the degree to which interpersonal relationships serve particular needs. Sherbourne and Stewart (1991) distinguish five categories of functional social support:

1. Emotional support: for example, feeling that there is someone to confide in who will be empathetic, someone with whom to share private thoughts and fears.
2. Informational support: e.g., feeling there is someone whose advice you value, who can offer information, guidance or feedback.
3. Tangible support: more practical support such as behavioural assistance or material aid.
4. Affectionate support: e.g., whether there is someone who will show you love and affection
5. Social companionship: the availability of other people to do fun things with you. This concept is also referred to as positive social interaction, 'belongingness', and social integration.

This paper focuses on *perceived* functional support, rather than received support, as the latter may be confounded with need. The fact that a person does not receive support during a given time period does not necessarily mean that they are unsupported (Sherbourne & Stewart, 1991).

Social networks can be seen as the structure through which perceived social support is provided (Lin, Dean & Ensel, 1981). However, social networks have a variety of functions of which the provision of social support is but one (O'Reilly, 1988). Seeman and Berkman (1988) confirm that the two concepts are independent, finding that the characteristics of someone's network and social support are not so highly correlated as to make them interchangeable.

### **The impact of stroke and aphasia on social support**

Stroke is the most common cause of long-term disability in England and Wales (Department of Health, 1998). More than 50% of people who survive a stroke are left with physical disabilities and at least 15% with aphasia (Wade, 1994). A number of studies have noted that size of social networks reduces post stroke. For example, Astrom, Adolfsson, Asplund and Astrom (1992a) describe a 'disintegration' in the social network over the first 3 months post stroke; Knapp and Hewison (1998) found that stroke survivors became isolated from their social networks in the first 6 months post stroke. Astrom et al. (1992a) report a reduction in contacts with friends,

neighbours and relatives. Various researchers (Belanger, Bolduc & Noel, 1988; Astrom et al., 1992a) have noted that friendships appear particularly vulnerable. Those who do manage to maintain friendships describe a change of roles, becoming a passive recipient, e.g., receiving rather than initiating visits (Dowswell, Lawler, Dowswell, Young, Forster & Hearn, 2000). However, Belanger et al. (1988) and Astrom et al. (1992a) found that contacts with children remained relatively unchanged.

In terms of the role of social support post stroke, a number of studies have found that functional social support is associated with reduced levels of depression (Robinson, Murata & Shimoda, 1999; Tsouna-Hadjis, Vemmos, Zakopoulos & Stamatelopoulos, 2000) and improved functional recovery (Glass & Maddox, 1992) over the first six months post stroke. Emotional support in particular appears to be useful in aiding recovery in this acute period (Glass & Maddox, 1992; Robertson & Suinn, 1968). In the chronic period post stroke, various studies have found positive associations between life satisfaction and measures of social networks (Astrom, Asplund, & Astrom, 1992b; Osberg, DeJong, Haley, Seward, McGinnis, & Germaine, 1988); well-being and social integration (Belanger et al., 1988); and well being and social networks (Wyller, Holmen, Laake & Laake, 1998).

People with aphasia, because of their communication problems, are often underrepresented in studies looking at stroke survivors. Indeed, many studies analysing social support exclude people with aphasia (Clarke, Black, Badley, Lawrence, & Williams, 1999; Friedland & McColl, 1987; 1992). Others used proxy responses; e.g., Astrom et al. (1992a & b) excluded people with severe aphasia and used proxy respondents for those who were 'unable to co-operate'; Wyller et al. (1998) used a nurse to assist those who 'needed help' completing the questionnaires. Others gave no information as to how the person with aphasia may have been facilitated in their responses (Dowswell et al., 2000; Glass & Maddox, 1992; Tsouna-Hadjis et al., 2000). Aphasia presents specific challenges, so it is not clear the extent to which the findings from stroke studies can be generalised to this population.

Aphasia potentially deprives a person of one of the primary ways of maintaining social relationships: language. This group then faces particular challenges in maintaining social networks. Parr, Byng and Gilpin (1997) conducted a qualitative research project, which gave insight into how aphasia affects individuals. A commonly described phenomenon was the sense of isolation. Aphasic people described themselves as 'cocooned in this

lonely shell' and 'stuck inside'. Sarno (1997) cited a survey conducted by the National Aphasia Association of the US in which 90% reported social isolation as their primary problem. Over 75% felt non-aphasic people often avoided contact because of difficulty communicating. There is, indeed, research evidence suggesting language difficulties are detrimental to social functioning over and above the social consequences of having a stroke. Zemva (2004) studied 64 people post-stroke: those with aphasia differed from those without in terms of social role functioning and isolation from friends. In their study of 30 people with aphasia, Cruice, Worrall, Hickson and Murison (2003) found that participants with better communication ability had fewer social limitations. As Parr et al. (1997, p. 44) comment: 'language is the currency of relationships [...] aphasia reduces the influence of one person in what was once a two-way process.'

In summary, aphasia can have considerable negative social consequences, which can impact on people's well-being and quality of life. This study aimed to explore the social network and perceived social support of people with chronic aphasia. It also looked at the relationship between these two social indicators and health related quality of life (HRQL). HRQL reflects the impact of a health-state (in this study: aphasia) on a person's ability to lead a fulfilling life (Bullinger, Anderson, Cella & Aaronson, 1993). It incorporates the individual's subjective evaluation of his/her physical, mental/emotional, family and social functioning (Berzon, Hays & Shumaker, 1993)<sup>1</sup>.

Specifically, the following research questions were addressed:

1. What is the social network of people with chronic aphasia?
2. What is the nature of perceived social support for people with chronic aphasia?
3. What is the relationship between perceived social support and social network for this population?
4. How do the different 'functions' of perceived social support correlate with HRQL?
5. What is the relationship between social network and HRQL in this population?

## **METHODS**

## **Design and participants**

A cross sectional, interview-based study was carried out. Data were collected on aphasia, perceived social support, social network, HRQL, stroke and demographic variables. Participants were recruited from 2 Speech and Language Therapy (SLT) Service Providers (NHS Trusts), one inner city and one semi-rural, and a not-for-profit organisation for people with aphasia. The targeted population was people with chronic aphasia in the Southeast of England. The inclusion criteria were: aphasia due to a stroke, at least 1 year post onset, no known pre-stroke history of severe cognitive decline or mental health problems and living at home prior to the stroke.

## **Procedure**

In the participating sites, review of SLT lists was undertaken to identify eligible participants. The Speech and Language Therapists confirmed that potential participants met the eligibility criteria and that they had no considerable hearing problems that could affect their performance in an interview task. Consent was obtained from eligible participants in writing at least 2 days after information giving (DoH, 2001). All the participants were interviewed at home or in their SLT site. Participants' aphasia was screened with the Frenchay Aphasia Screening Test (FAST) (Enderby, Wood & Wade, 1987). If people scored less than 7/15 on the receptive domains of the FAST it was assumed, based on our previous research (Hilari & Byng, 2001), that they could not reliably respond to the questionnaires that were used. On these occasions, with the participant's consent a proxy respondent was used (usually the spouse/partner or the main carer of the person with aphasia). These cases were excluded from the current analysis.

## **Measures**

Information on demographic, stroke related and comorbidity variables were collected from the participants' SLT notes. They were confirmed and supplemented through a short interview with the participants.

Health related quality of life: HRQL was assessed with the Stroke and Aphasia Quality of Life scale- 39 item version (SAQOL-39) (Hilari, Byng, Lamping & Smith, 2003a). The SAQOL-39 has been tested with people with chronic aphasia in the UK and has excellent psychometric properties (Hilari et al., 2003a). The scale comprises questions about the effects of stroke and aphasia on people's lives that group into 4 domains: physical, psychosocial, communication and energy. Although the SAQOL-39 includes items on social and family life and



social activities, it does not really tap on social support as its low correlation with the Social Support Survey (SSS) reveals ( $r = 0.19$ ) (Hilari, Wiggins, Roy, Byng & Smith, 2003b). The response format is a 5-point scale ranging in some questions from 'couldn't do it at all' (1) to 'no trouble at all' (5) and in others from 'definitely yes' (1) to 'definitely no' (5). The response scale was treated as an equal interval scale. Scores are summed and averaged and they range for the sub-domains and the whole scale from 1 to 5 with higher scores indicative of higher quality of life.

Perceived social support: Perceived social support was assessed with the Medical Outcomes Studies (MOS) Social Support Survey (SSS) (Sherbourne & Stewart, 1991). The SSS assesses the perceived availability of five types of support (tangible, emotional, informational, social companionship and affectionate support). The authors recommend combining the emotional and informational subscales into one support scale. In this study we were interested to examine the different effects of informational and emotional support and we have therefore analysed them separately. The SSS has a sound theoretical basis and good psychometric properties, which were tested on a group of chronically ill outpatients. The authors recommend scoring and using the subscales separately as use of an overall score to test hypotheses would make it difficult to determine which functions of support lead to different outcomes. In order to reduce respondent burden, the scale is designed to be brief and does not ask about who provides the support. The items of the SSS are designed specifically to be short, simple and easy to understand. Minor modifications were made in this study, however, in order to ensure it was communicatively accessible (such as reducing the number of items presented on each page). The response format is a 5-point scale going from 'none of the time' (1) to 'all of the time' (5), which was treated as an equal interval scale. Scores for each subscale are summed and averaged and they range from 1 to 5, with high scores indicative of greater levels of perceived support.

Social network: Existing social network scales commonly place considerable demands on the respondent. For example, the Social Support Inventory for Stroke Survivors (McColl & Friedland, 1989) consists of 75 questions and the language used is complex. In this study an effort was made to keep respondent burden to a minimum. For this reason, we did not use one of the existing complex measures. We collected data on the two aspects of social network that are most often described as significant: social network size and frequency of contacts (Stansfeld, 2000).

Size of network has been shown to be significantly associated with mortality (Berkman & Syme, 1979; House et al., 1982) in the general population. It has also been found to be an important indicator of life satisfaction and well-being in chronic stroke survivors (Astrom et al., 1992b). In considering what elements of the network to measure, we chose those known to be meaningful to the aphasic population: spouse/partner; children; close friends; close relatives; group membership/voluntary activities (Parr et al. 1997; Code, 2003; Hilari et al., 2003b). Network size was calculated by adding together the spouse/partner; number of children; number of relatives; number of friends; number of group memberships.

A criticism levelled at simpler measures of social networks, such as calculating size alone, is that they fail to provide insight into the dynamics of how the network is functioning (Bowling, 1997). Some additional questions were therefore asked in order to gain insight into changes in the use of network from before the stroke, focusing on changes in frequency of contact. Participants were asked how often they saw their children, relatives and friends compared to before the stroke. Possible responses included much less, less, the same, more or much more than before the stroke. For the purposes of this study, 'much less' and 'less' were scored as 0, 'the same' was scored as 1, and 'more' and 'much more' were scored as 2.

### **Data analysis**

Descriptive statistics were used to explore the social network and perceived social support of participants. Correlation was used to explore a) the relationship between social network size and perceived social support; and b) the relationship between the subscales of perceived social support and HRQL. Gender differences and the relationship between social network variables and HRQL was examined using correlation, t-tests, and ANOVAs as appropriate. All statistical analysis was carried out using SPSS 11.5 for Windows, and all statistical tests were 2-tailed.

## **RESULTS**

### **Participants**

One hundred and sixteen eligible participants were identified and were asked to take part in the study. Ninety-five people (82%) agreed to take part. No further information is available on the 21 people who did not take part as we did not have their consent for their records to be reviewed. Of the ninety-five people who took part in the study, 12 had such severe language problems (FAST receptive score < 7/15) that they were unable to self-report on the questionnaires that were used. For those participants proxy respondents were used and their results are not reported here.

Table 1 details the characteristics of the remaining 83 participants. The majority were male (62.7%) and they ranged in age from 21 to 92 (mean 61.6±15.4). About 43% were over 66 years old and 15.7% were between 21 and 45. The majority of the sample were white (78.3%) and married/had a partner (62.6%). Although almost 56% of the sample were of working age ( $\leq 65$ ) only 6% were involved in some type of work (part-time or voluntary work and students). No participants were in full-time work. Participants' socioeconomic class was determined using the system of the Office of National Statistics (Rose & O' Reilly, 1997), which is based on occupation. Participants were classified according to their last occupation before the stroke, using the collapsed version of the socioeconomic classification (SEC). According to this criterion, approximately 35% were professionals and managers, 35% were other administrative and clerical workers, or own account non-professional and supervisors, or technicians and related workers, 25% were intermediate or other workers and 5% had never worked. In terms of the severity of their aphasia, participants' scores ranged from 8-30/30 on the FAST. Only 9 participants (10.8%) had severe aphasia (FAST score  $\leq 10$ ) and 45 (54.2%) had mild aphasia (FAST score 21-30).

[Table 1 about here]

### **1. Social network of people with chronic aphasia**

The size of participants' network had a distribution that was negatively skewed. The mean score (SD) was 10.1 (6.9) and the mode was 4. The range was large, varying from 1 to 40. Participants' severity of aphasia did not affect the size of their network (Spearman's rho = .02.  $p \leq .857$ , ns). Figure 1 details the individual components of network size. About 63% of participants were married/had a partner and 37% were divorced or their partner had died or were single. In terms of children, 63.4% had 1-3 children and 20.5% had no

children. The mean (SD) number of close relatives was 2.7 (4.08) (range: 0 to 25). Where participants reported, e.g., they had two to three relatives, then this was reported as 2.5, to maintain accuracy. Around 29% of participants were not in contact with any relatives, and around 32% were in contact with only 1 or 2 relatives. The mean (SD) number of close friends was 3.01 (3.5) (range 0-20). About 30% reported no friends. A number of participants drew attention to the fact that they had lost friendships as a result of the stroke. For example, one participant, when asked how many friends they had, answered 'A lot, they all ran away' (coded as 0). The mean (SD) number of group memberships was 1.64 (1.57) (range 0-8). 25% were not members of any group while 20.4% were members of 3 or more groups.

[Figure 1 about here]

Figure 2 details the frequency of contact with children, friends and relatives. In relation to children, of the participants who had children, 71.2% had the same amount of contact with their children as before the stroke, 13.7% had less and 15.1% had more contact. Of those who reported having close relatives, contact was the same for 42.1%, less for 24.6%, and more for 33.3%. 12% of participants said they had no friends prior to the stroke. Of the remaining participants, 63.9% had less contact with their friends; 33.3% had the same amount; 4.3% had more contact.

[Figure 2 about here]

## **2. Perceived social support**

The scores for perceived social support (SSS) ranged from 1 to 5 but had a positively skewed distribution, suggesting that participants overall felt well supported. Participants' severity of aphasia did not affect their perceived social support (Spearman's  $\rho = .01, p \leq .928$ ). The mean (SD) for perceived social support was 3.69 (.95). In terms of the different subscales, the mean score of tangible support was 4.21 (.98); the mean score of the other four subscales varied from 3.37 (1.15) (social companionship) to 3.77 (1.28) (affectionate support).

### 3. Relationship between perceived social support and social network

Analysis was carried out to see if the size of network and the mean scores of the SSS subscales were significantly correlated (see table 2). This showed that there was a significant correlation between size of network and SSS (Spearman's  $\rho = .229$ ,  $p \leq .037$ ). The level of correlation (moderate) suggested the two variables are independent.

Only two of the perceived social support subscales were significantly correlated with the network size: informational support (Spearman's  $\rho = .302$ ,  $p \leq .006$ ) and social companionship (Spearman's  $\rho = .259$ ,  $p \leq .018$ ).

[Table 2 about here]

### 4. Perceived social support and health related quality of life (HRQL)

HRQL as measured by the SAQOL-39 was normally distributed (Kolmogorov-Smirnov test ns at  $p \leq .2$ ) with a mean (SD) of 3.27 (0.7), a median of 3.26 and scores ranging from 1.72 to 4.46.

Table 3 details the correlations between perceived social support and HRQL. Only the SAQOL-39 mean score was used (rather than its subdomains) to avoid multiple comparisons. Overall perceived social support did not significantly correlate with HRQL (Spearman's  $\rho = .170$ ,  $p \leq .125$ ). Two perceived social support subscales, however, were significantly correlated with HRQL: informational support (Spearman's  $\rho = .257$ ,  $p \leq .019$ ) and social companionship (Spearman's  $\rho = .24$ ,  $p \leq .029$ ).

[Table 3 about here]

### 5. Social network and HRQL

Size of network was not significantly correlated with HRQL (Spearman's  $\rho = .197$ ,  $p \leq .074$ ) nor were any of the individual components of the network, although group membership approached significance (Spearman's  $\rho = .193$ ,  $p \leq .08$ ).

In terms of frequency of contact (see figure 3), we compared HRQL for those who saw their children less, the same, or more than before the stroke. Participants with the highest HRQL scores (3.40) saw their children at the same frequency as before the stroke. Participants who saw their children less than before the stroke had lower HRQL scores (2.88) and those who saw them more had the lowest HRQL scores (2.82). A one-way ANOVA showed that this pattern was significant ( $F(2,64)=4.58, p \leq .014$ ). We also compared HRQL for those who saw their relatives less, the same, or more. Again, participants with the highest HRQL scores saw their relatives at the same frequency; those who saw them more or less had lower HRQL scores and the difference was significant ( $F(2,56)=3.257, p \leq .046$ ). In terms of contact with friends, however, those who saw their friends more had the highest HRQL scores; those who saw them less had the lowest scores. These results were not significant ( $F(2,69)=.138, p \leq .871$ ).

[Figure 3 about here]

## DISCUSSION

This study looked at social support in people with chronic aphasia. A strength of the study was that 83 (out of 95) people with aphasia were able to self-report their answers, unlike many studies of stroke survivors that exclude this population because of their language problems. Of eligible participants, 82% took part in the study. This high response rate suggests the sample used was representative of the population targeted. Indeed, stroke is more common in men and in older people (Department of Health, 1998). In our sample 63% were male and 44% were over 65 years old. In the study area, 24% of the population is Black or Asian (Stewart, Dundas, Howard, Rudd & Wolfe, 1999) compared with 22% in our sample. There was, however, a difference in social class between our sample and the UK stroke population. Stroke is more prevalent in people from manual social classes, whereas 57% of our sample was from non-manual social classes. This probably reflects the geographical area from which the sample was drawn.

### Main findings

*Social network and perceived social support*

To gain insight into how aphasia impacts on social networks, information was obtained on how the frequency of contact with friends and family had changed since the stroke. The literature review suggests that families 'can be held together with tradition and with the rituals of everyday life' while friendships 'can lack the scaffolding of habit' and are more vulnerable to language disability (Parr et al., 1997, p.57). Our findings supported this analysis. Most people had maintained or increased contact with their children (86.3%) and their relatives (75.4%) since the stroke. However, a very different picture emerged when looking at friendships: 63.9% had less contact with friends and 30% could not name a single close friend. These statistics suggest friendships are often lost following onset of aphasia.

In terms of the size of people's networks, the mean was 10 but the mode was only 4. This is smaller than the average for the general population, which is estimated to be between 8 and 15 members (Schulz & Rau, 1985). It suggests that a number of participants were relying on only a few network members for all support needs. This arguably fits in to a pattern of losing contacts with a wider circle of friends noted above. As suggested in the literature, group membership was indeed a factor in many of the participants' networks, with people attending on average 1.64 groups. Since none of the participants had returned to full-time employment following stroke, attending groups may have taken on some of the social functions of the work place.

Looking at perceived social support, participants' scores indicated they felt overall well supported, in particular in the area of tangible support. Tangible support was not correlated with network size, suggesting that perhaps this kind of support can be effectively provided by a small number of network members. The two subscales that correlated significantly with size of network were social companionship (Spearman's rho = .259,  $p < 0.018$ ) and informational support (Spearman's rho = .302,  $p < 0.006$ ). This may suggest that informational support is perhaps achieved through being connected to a wider network. The concepts of social companionship and social networks arguably serve similar functions: that of feeling embedded in your community, with the sense of identity that this confers.

#### *Associations with HRQL*

At first glance it would seem that social support has no significant impact on the HRQL of people with chronic aphasia, as neither overall size of social network nor overall perceived support were significantly correlated

with HRQL in this sample. However, to conclude from this that social support plays no role would be premature, as in a more detailed analysis, some significant differences and interesting patterns do emerge.

Two aspects of perceived social support were associated with better HRQL: social companionship and informational support. That social companionship was associated with HRQL replicates the findings of research into other chronic illness: Symister and Friend (2003) found the social companionship subscale the most important for predicting decreases in depression and increases in optimism in end-stage renal disease patients. From a theoretical point of view, Cohen and Wills (1985) suggest that the function of social companionship is most likely to be beneficial when it addresses a specific need: as discussed above, the loss of friendship and social interaction is a factor for this population.

Informational support was also significantly associated with HRQL. Although the level of the actual correlation was low, this finding may reflect the needs of this specific population: access to information can often be problematic for people with aphasia, and this can be an ongoing issue (Parr et al., 1997). Aphasia may make it difficult to read information leaflets, find out about and fill in benefits forms, write letters, make phone calls, or understand verbal information that is given rapidly in complex language. While the general population may be relatively self-reliant in being able to access information from a variety of sources, someone with aphasia may be more reliant on supportive network members to help them access and understand the information they need.

By contrast, tangible support was not correlated with HRQL. As suggested by Glass and Maddox (1992) tangible support can promote helplessness and dependency, which may be unhelpful in the formation of a new stroke identity. In their own study, stroke survivors made better recovery receiving moderate rather than high levels of tangible support. Norris, Parris Stephens and Kinney (1990) document the irritation reported by stroke survivors at receiving unwanted assistance with activities of daily living. Neither affectionate nor emotional support were significantly correlated with HRQL for this population of people with chronic aphasia. This fits Cohen and Wills' (1985) prediction that these types of support are most useful in acutely stressful periods.



Cohen and Wills (1985) suggest that when not experiencing acute stress, social networks may be important for good quality of life. Previous studies looking at chronic stroke survivors did indeed find that measures of well-being and life satisfaction were related to social network measures, as discussed in the introduction. However, in our study size of network did *not* significantly correlate with HRQL. This may in part be due to the focus on immediate network of close friends and relatives, rather than more distal acquaintances. Further, the measure used did not make reference to either pre-morbid network or satisfaction with network size which may have made it harder to detect a significant result. Alternatively, it may be that size of network is less important for this population. Interestingly, size of network was indeed significantly associated with HRQL for women ( $p \leq 0.043$ ) but not for men ( $p \leq 0.539$ ). The emphasis on close relationships with friends and relatives may reflect a pattern of intimate and confiding social support more associated with female preferences (Antonucci & Akiyama, 1987). Another consideration is attitudes towards dependence, which may be expected to be high for this population. Nagurney, Reich and Newsom (2004) looked at the interaction between received support, a desire for independence, and gender in 118 older adults. They found that men with a high desire to be independent responded negatively to receiving support from their social network. Women's outcomes were unaffected by their desire for independence. Finally, this result may reflect gender differences in the marital relationship. Due, Holstein, Lund, Modvig, & Avlund (1999) note that men are likely to name their partner as their confidant, while women are more likely to have a confidant relationship with relatives or friends, arguably making their close circle of friends and relatives more important to them.

None of the individual components of social network size were significantly correlated with HRQL either. For example, it appears that neither having a partner, nor having children, contribute to higher HRQL scores. This is possibly intuitively surprising, and confounds many population samples, which tend to find a protective value in having a spouse (see Cohen & Wills, 1985, for an overview). Looking at the stroke literature, however, suggests that the picture may be more complex for this population. Labi et al. (1980) found that those who lived alone were less likely to reduce outside socialisation than those who lived in a family context. Further, those who cited their spouse as their significant other experienced the greatest decrease in social activity, whereas if they cited a friend they had a much greater chance of maintaining some kind of outside social life.

In terms of how frequency of contact interacted with HRQL, a striking pattern emerged. Those who had *more* contact with their children had the *lowest* HRQL scores, suggesting that more is not always better. Those who had the same amount of contact had the highest HRQL scores. Perhaps the most obvious interpretation is that increased contact suggests increased need, and therefore increased dependence; loss of independence may be expected to correlate with lower HRQL. There is also some suggestion in the literature of the conflicting emotions felt by many people in relation to changing family roles. Certainly, a theme that emerges in the qualitative literature is that many stroke patients express distress at feeling a 'burden' to their families. One patient in Dowswell et al. (2000) says 'There is a worry... it's mainly my concern for others... you can't help but feel that you're being a burden.' Dowswell et al. go on to describe the pain at the often sudden reversal of roles from being the one who cared for their family, to being the one cared for. The stroke survivor is not only contending with their own emotional reaction but also potentially feeling responsible for the impact of the stroke on the rest of the family. Given these conflicting feelings it is perhaps less surprising that there was not a neat positive correlation between having children/spouse and HRQL. A similar pattern emerged with relatives, with those experiencing the highest HRQL seeing their relatives the same amount as before the stroke, whereas those who saw them more had lower HRQL. Again, increased frequency of contact may be correlated with increasing loss of independence.

The pattern is different for friends. The more participants saw of their friends, the better their HRQL, although this pattern did not reach significance. This would seem to confirm the suggestion in the literature that friendships occupy a different function, less based on obligation, and possibly more likely to be providing emotional and social companionship support rather than tangible support (Wenger, 1994).

### **Clinical implications and future research**

In our sample of people with chronic aphasia, higher health-related quality of life was associated with increased social companionship and informational support; maintaining the same contact with your family and having more contact with your friends. Interventions at this chronic stage, therefore, may aim to help people achieve social integration. Therapy approaches aimed at increasing the conversation skills of people with aphasia and people in their immediate social context - family members, volunteers, care workers- may be one way of promoting social integration (e.g., Hopper, Holland & Rewega, 2002; Kagan, Black, Duchan, Simmons-Mackie

& Square, 2001; Lock, Wilkinson, Bryan, Maxim, Edmundson, Bruce et al., 2001). Other ways may be to work on increasing participation in activities of choice for people with aphasia (e.g., Lyon, Cariski, Keisler, Rosenbek, Levine, Kumpula et al., 1997), facilitating access to adult education (e.g., Wahrborg, Borenstein, Linell, Hedberg-Borenstein, & Asking, 1997; Elman, 1998) and offering group therapy that promotes people with aphasia's communication skills and confidence and gives them the opportunity to build new networks (e.g., Elman & Bernstein-Ellis, 1999; Pound, Parr, Lindsay & Woolf, 2000).

An alternative approach to facilitating social companionship and informational support is to dismantle barriers to inclusion. These may include the attitudes of other people, features of the physical environment, and societal conventions. In working to remove these barriers, various authors have argued for greater public awareness of aphasia (Code, 2003; Elman, Ogar & Elman, 2000). Indeed surveys of the population have revealed reduced public awareness of aphasia (Code, Simmons-Mackie, Armstrong, Stiegler, Armstrong et al., 2001; Simmons-Mackie, Code, Armstrong, Stiegler & Elman, 2002). Elman et al. (2000) suggest limited public awareness results in less empathy and understanding for re-integrating into the community. Others have suggested targeting training and resources to community members (e.g. doctors, lawyers) (Kagan, 1998). Informational access could be improved through presenting information so that it is accessible to people with aphasia (e.g., larger font, key words in bold). An alternative approach is to empower the aphasic individual, for example through assertiveness training (Pound et al., 2000).

Still, further efficacy studies of the different types of intervention aimed at providing a sense of social companionship and promoting social integration at the chronic stage are needed. Simmons-Mackie (1998) argues that there is not yet enough evidence to know whether provision of supported conversation groups, communication partners and other 'protected' social opportunities are more effective than communication intervention designed to ensure successful use of language in social interaction and ultimately inclusion in the wider community. Moreover, studies aimed at analysing the process by which friends are lost following stroke and aphasia may help to inform therapy interventions. For example, one could examine whether it is more valuable (and/or achievable) to aim to help people maintain pre-existing friendships, or to facilitate the formation of new friendships.

Lastly, in considering this study's main findings, many interpretations are necessarily speculative due to the limitations of this study. To increase the feasibility of the study and reduce respondent burden we did not explore in more depth the dynamics of the social support process. This might include more detailed information about the social network and support processes, including social support experienced previous to the stroke; and semi-structured interviews to provide qualitative information. Information on negative social interactions could also provide further insights. For example, Norris et al. (1990) looked at family interactions following recovery from stroke and found that negative emotional interactions accounted for 11% in variance for personal adjustment. In terms of the study design, in future studies a control group of both stroke patients and 'healthy' population matched for demographic variables would allow the effects of aphasia to be distinguished from more general effects of chronic illness and age. Further, a longitudinal design would help to establish whether there is a temporal dimension to grief and social support.

### **Summary and conclusion**

This study explored the social network and perceived social support of people with chronic aphasia and their relationship to health-related quality of life. We found that most participants maintained contact with family but not with friends; those who saw their children and relatives the same as before the stroke had higher HRQL than those who saw them either more or less; size of social network was associated with HRQL for women but not for men; and that social companionship and informational support were significantly correlated with HRQL.

The clinical implications of these findings were discussed. These included interventions aimed at promoting social integration, such as supported conversation groups; ways for working with the existing social network; and ways to enhance social companionship and informational support. Future research directions were explored, such as further research looking at how aphasia affects the processes of forming and maintaining social contacts, as well as evaluating intervention studies aimed at enhancing social support.

### Footnote

<sup>1</sup> Quality of life is a related but broader term than HRQL, often related to a person's culture and value systems (WHO, 1993) and incorporating factors like a safe environment and material well-being. This study has looked at HRQL. Most of the literature reviewed here has also assessed what is commonly viewed now as HRQL, but have used the term quality of life. In reporting other people's work we have used the terms they used.

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**Table 1: Respondents' characteristics (N=83)**

<b>Variable</b>	<b>n (%)</b>
<b>Gender</b>	
Female	31(37.3)
Male	52 (62.7)
<b>Age</b>	
Mean [SD]	61.67 [15.47]
Range	21-92
21-45	13 (15.7)
46-65	34 (41)
66+	36 (43.4)
<b>Stroke type</b>	
Ischaemic	36 (43.4)
Haemorrhagic	16 (19.3)
Unknown	31 (37.3)
<b>Time post stroke</b>	
Mean in years [SD]	3.5 [3.09]
Range	1y 1m-20y 10m
1-2 years post onset	26 (31.3)
>2-4 years post onset	31 (37.3)
>4 years post onset	26 (31.3)
<b>Ethnic group</b>	
Asian	7 (8.4)
Black	11 (13.3)
White	65 (78.3)
<b>Marital status</b>	
Married	42 (50.6)
Has partner	10 (12)
Single	14 (16.9)
Divorced or widowed	17 (20.5)
<b>Socioeconomic status (revised SEC)</b>	
Professional/senior manager	23 (27.7)
Ass. Professional/ junior manager	6 (7.2)
Other admin. And clerical worker	13 (15.7)
Own account non-professional	5 (6)
Supervisor, technician and related worker	11 (13.3)
Intermediate worker	9 (10.8)
Other worker	12 (14.5)
Never worked/other inactive	4 (4.8)
<b>Employment status</b>	
Retired before stroke	31 (37.3)
Inactive because of stroke	47 (56.6)
Some p/t or voluntary work	3 (3.6)
Student	2 (2.4)
<b>Aphasia severity (FAST score)</b>	
Severe (1-10)	9 (10.8)
Moderate (11-20)	29 (34.9)
Mild (21-30)	45 (54.2)

**Table 2: Correlations (Spearman's rho) between perceived social support and social network (N=83)**

<b>MOS SSS</b>	<b>Social network size</b>	<b>p</b>
<b>Mean SSS score</b>	.229	.037*
<b>Emotional subscale</b>	.211	.055
<b>Informational subscale</b>	.302	.006**
<b>Tangible subscale</b>	.162	.144
<b>Affectionate subscale</b>	.205	.064
<b>Social companionship subscale</b>	.259	.018*

\* probability significant at the .05 level

\*\* probability significant at the .01 level

**Table 3: Correlations (Spearman's rho) between perceived social support and HRQL (N=83)**

<b>MOS SSS</b>	<b>SAQOL-39 mean score</b>	<b>p</b>
<b>Mean SSS score</b>	.170	.125
<b>Emotional subscale</b>	.172	.223
<b>Informational subscale</b>	.257	.019*
<b>Tangible subscale</b>	-.064	.566
<b>Affectionate subscale</b>	.047	.67
<b>Social companionship subscale</b>	.24	.029*

\* probability significant at the .05 level

Figure 1: Individual components of network size

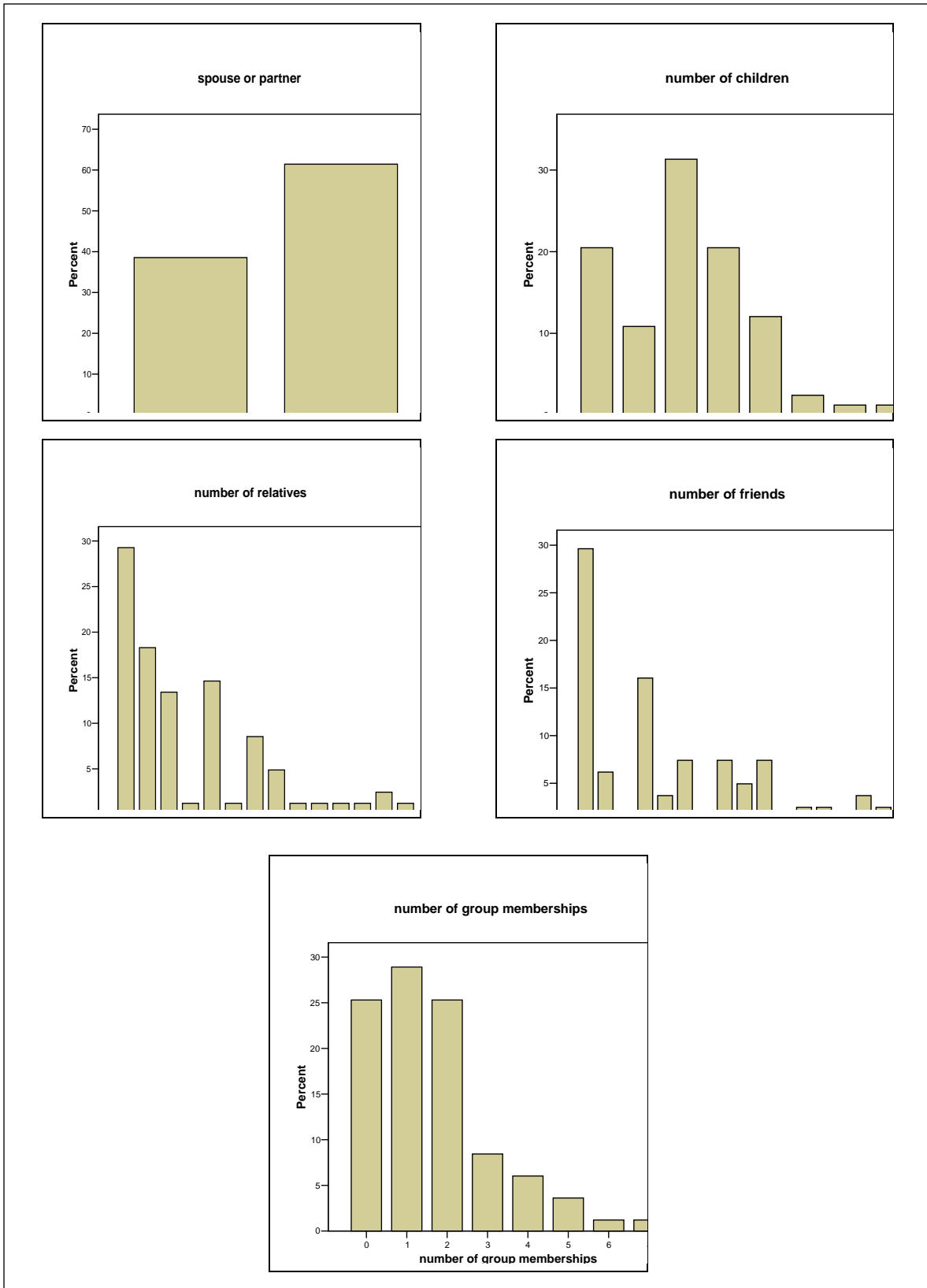




Figure 2: Frequency of contact with children, friends and relatives

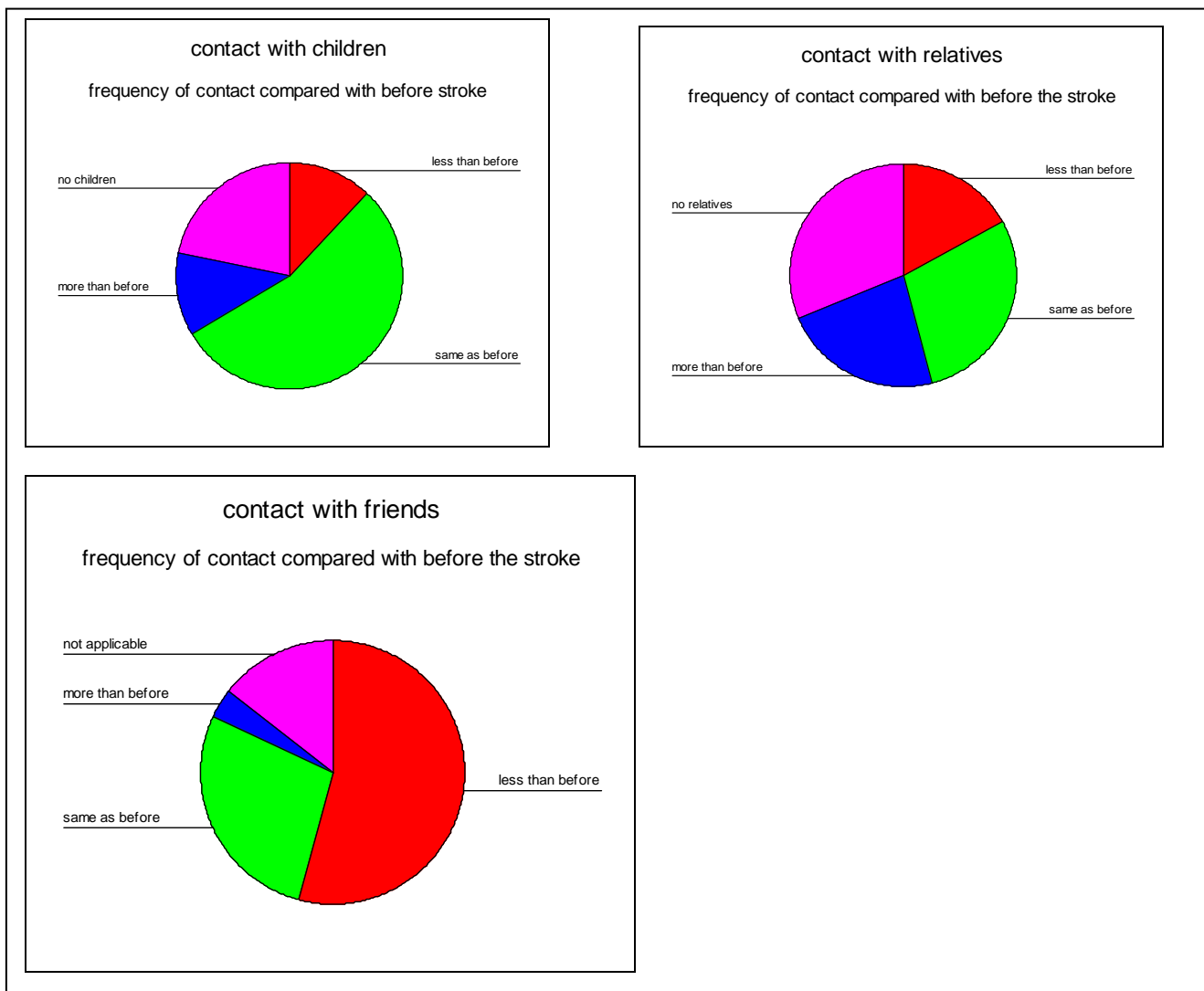


Figure 3: Frequency of contact with social network and HRQL (N=83)

