



City Research Online

City, University of London Institutional Repository

Citation: Hilari, K. and Northcott, S. (2016). "Struggling to stay connected": comparing the social relationships of healthy older people and people with stroke and aphasia. *Aphasiology*, 31(6), pp. 674-687. doi: 10.1080/02687038.2016.1218436

This is the accepted version of the paper.

This version of the publication may differ from the final published version.

Permanent repository link: <https://openaccess.city.ac.uk/id/eprint/15252/>

Link to published version: <http://dx.doi.org/10.1080/02687038.2016.1218436>

Copyright: City Research Online aims to make research outputs of City, University of London available to a wider audience. Copyright and Moral Rights remain with the author(s) and/or copyright holders. URLs from City Research Online may be freely distributed and linked to.

Reuse: Copies of full items can be used for personal research or study, educational, or not-for-profit purposes without prior permission or charge. Provided that the authors, title and full bibliographic details are credited, a hyperlink and/or URL is given for the original metadata page and the content is not changed in any way.

“Struggling to stay connected”¹: comparing the social relationships of healthy older people and people with stroke and aphasia.

Katerina Hilari and Sarah Northcott

Division of Language and Communication Science, City University London, London, UK

Corresponding author:

Dr Katerina Hilari

Division of Language and Communication Science

City University London

Northampton Square

London EC1V 0HB

k.hilari@city.ac.uk

¹ Quote from 2014 American drama film *Still Alice*

“Struggling to stay connected”: comparing the social relationships of healthy older people and people with stroke and aphasia.

Abstract

Background: Having a stroke and aphasia can profoundly affect a person’s social relationships. Further, poor social support is associated with adverse post-stroke outcomes such as psychological distress, worse quality of life, and worse recovery. To date, no study has used complex measures of social network and perceived social support to compare stroke survivors with aphasia, without aphasia, and the general older population. A better understanding of which aspects of social support are most affected by stroke and aphasia may inform stroke services.

Aims: To compare the social networks and perceived functional social support of people following a stroke, with and without aphasia, and healthy older adults.

Methods & Procedures: Cross-sectional interview-based study. People with a first stroke were recruited from two acute stroke units and interviewed six months post onset. We recruited 60 stroke participants without aphasia, average age 69.8 ($SD = 14.3$), and 11 stroke participants with aphasia, average age 66.5 ($SD = 13.7$). One hundred and six healthy older adults were recruited via the community, average age 62.8 ($SD = 9.5$). All participants completed the Medical Outcomes Study Social Support Survey and the Stroke Social Network Scale. One-way independent groups ANOVAs were used to compare stroke participants with aphasia, stroke participants without aphasia and healthy older adults.

Outcomes & Results: After adjusting for multiple comparisons ($p < .004$), there was a significant difference on overall social network between the three groups ($p < .001$), with those with aphasia scoring significantly lower than healthy older adults ($p < 0.001$). The difference between healthy older adults and people with aphasia on the Friends domain of the social network scale was also

significant ($p = .002$). There was no significant difference between the three groups on overall perceived functional social support.

Conclusions: People with aphasia have less diverse social networks than healthy older adults, with friendships particularly affected. Stroke services should monitor for social isolation, and consider ways to support people following a stroke in maintaining or establishing diverse social networks.

Keywords: social support; social network; stroke; aphasia

Introduction

Strong social support is consistently associated with higher subjective well-being (Pinquart & Sorensen, 2000); and reduced risk of depression (Teo, Choi, & Valenstein, 2013). There is also strong evidence that those with diverse well-functioning social networks have increased longevity (Holt-Lunstad & Smith, 2012) and higher morale (Litwin, 2001). These patterns are also found in studies exploring social support/networks following a stroke: those with reduced social support or who are socially isolated are more likely to be depressed (Northcott, Moss, Harrison, & Hilari, 2015) and experience an adverse event such as a second stroke (Boden-Albala, Litwak, Elkind, Rundek, & Sacco, 2005). It is therefore of concern that there is considerable evidence that having a stroke challenges a person's ability to maintain a strong social network. A recent systematic review exploring social support post stroke found that stroke survivors are at risk of losing contact with friends and acquaintances, take part in fewer social activities, family functioning is placed under strain, and the overall size of their network becomes smaller (Northcott, Moss, et al., 2015).

Having aphasia appears to create particular challenges in maintaining strong social relationships. In a companion qualitative study comparing the experiences of those with and without aphasia one year post stroke, those with aphasia were more likely to experience hurtful negative responses from others, to report that the substance of their friendships had altered (e.g. conversations were less likely to be two-way, it was harder to join in group conversations), and were more likely to report losing entire friendship circles (Northcott & Hilari, 2011). Another study found that 30% of people with chronic aphasia reported having no close friends at all, while 64% reported seeing their friends less than before the stroke (Hilari & Northcott, 2006). Having aphasia has also been reported to change family dynamics and alter family roles, for example, challenging a person's ability to read a bed-time story to

their child, or contribute to family decision making (Fotiadou, Northcott, Chatzidaki, & Hilari, 2014).

While many studies have documented that stroke survivors report their social relationships have changed as a result of the stroke (Dalemans, de Witte, Wade, & van den Heuvel, 2010; Haun, Rittman, & Sberna, 2008; Vickers, 2010), fewer studies have placed these observations in the context of an age-matched healthy population. Those that have consistently find that friendships and social activities appear to be vulnerable. Cruice, Worrall, and Hickson (2006) explored the social networks and social activities of people with post-stroke aphasia compared to healthy older people of similar age and education. They found that those with aphasia took part in significantly fewer social activities, and were less satisfied with their social activities than controls. In terms of the size of network, they had significantly smaller networks than healthy controls, with fewer 'friends' relationships. Ross and Wertz (2003) also compared people with aphasia against healthy controls in order to differentiate which aspects of quality of life, as measured by the WHO-QOL short form, most clearly differentiated between the two groups. One of the three distinguishing facets was in the social relationships domain, specifically, satisfaction with support received from friends. A similar pattern was found in a general stroke study: Astrom, Adolfsson, Asplund, and Astrom (1992) compared aspects of social network of those who were three months post stroke with data from a national survey. They reported that contact with friends and relatives was significantly reduced compared with controls, although contact with children was comparable.

These studies suggest significant differences in how social networks function when comparing healthy older adults and people who have had a stroke. We wanted to investigate further whether these differences were being driven by the aphasia, or whether stroke

survivors with and without aphasia report similar patterns of change in their social networks. We also wanted to explore whether using a complex measure of social network functioning could further inform our understanding, and enable a systematic examination of which aspects of the network most distinguish the three groups. Bowling (1997) defines a social network as ‘the web of identified social relationships that surround an individual and the characteristics of those linkages’ (p.90). Measures of social network functioning may include size and composition of network (for example, whether the members are family, friends, neighbours, other acquaintances), participation in community activities, frequency of contact between members, and proximity (how close by the network members live to one another) (Berkman, Glass, Brissette, & Seeman, 2000; Bowling, 1997). Complex measures of social network have been shown to be more predictive of outcomes such as longevity than simpler measures such as marital status or living arrangements (Holt-Lunstad & Smith, 2012).

Another area that has not yet been explored is whether functional social support is significantly different between stroke survivors with and without aphasia and healthy older people. The topic is of importance as low levels of functional support have been associated with adverse post stroke outcomes, such as psychological distress, worse quality of life and poorer recovery in rehabilitation (Northcott, Moss, et al., 2015). The literature describes a number of support functions, including: emotional support (provision of support that makes a person feel loved, esteemed, and accepted); informational support (provision of feedback, guidance, advice or information); tangible support (including financial assistance, or practical help such as doing the shopping or assistance with activities of daily living); and social companionship support (spending time with someone in leisure or recreational activities, having fun with others) (Berkman et al., 2000). A further distinction can be made between ‘perceived’ and ‘received’ functional support. Ditzen and Heinrichs (2013) define received

support as ‘an intended and observable act of help (including all functional types)’ whereas perceived support is ‘understood as a general expectation of being supported.’ Perceived functional support is in fact not strongly associated with actual support received: in a meta-analysis of 23 studies, the association between the two concepts was $r = .35$ (Haber, Cohen, Lucas, & Baltes, 2007). Perceived support has been found to be more strongly associated with health-related quality of life and depression than received support, both post stroke (Northcott, Moss, et al., 2015), and in the general population (Haber et al., 2007). For this reason, we chose to explore perceived functional support.

While received functional support may vary according to need and life circumstances (Sherbourne & Stewart, 1991) perceived functional support is understood to remain relatively stable in the general population (Sarason, Sarason, & Shearin, 1986). Nonetheless, there is some evidence that those who become disabled (Taylor & Lynch, 2004) or unwell with cancer (Lee et al., 2011; Moyer & Salovey, 1999) perceive themselves to be less well supported. Understanding how stroke and aphasia impacts on perceived functional support compared to healthy older adults would increase our knowledge of the stability of this construct in the event of long-term disability.

A better understanding of how social networks and functional support differ between the stroke population and the general elderly population may enable stroke services to focus on the domains which appear to be most vulnerable. Further, a clearer understanding of the differential impact of aphasia may help to clarify whether this subgroup have particular support needs. This study therefore aimed to directly compare the social networks and perceived functional support of people with stroke and aphasia, stroke without aphasia and healthy older adults.

Methods

Design and participants

Participants with stroke reported here were from a larger stroke cohort study on quality of life, psychological distress and social networks, which has been previously reported (Hilari, 2011; Hilari et al., 2010; Northcott & Hilari, 2013). Eligibility criteria comprised: admitted to hospital with a first ever stroke; stay in hospital for at least three days; > 18 years old. People were excluded if they: did not live at home prior to the stroke; had a known history of mental health problems or cognitive decline prior to the stroke; had other severe or potentially terminal co-morbidity; were unable to give informed consent; did not speak English pre-morbidly (self and/or family report). Those with any severity of expressive aphasia, and mild to moderate receptive aphasia, as determined by the Frenchay Aphasia Screening Test (Enderby, Wood, Wade, & Hewer, 1987) were included. Those with severe receptive aphasia were asked to nominate proxy responses, and these responses are analysed elsewhere.

Healthy older adults were recruited from the same area as stroke participants. They were recruited and interviewed by student Speech and Language Therapists in their last year of training from community groups, organisations for older people (e.g. University of the third age) and through acquaintances/friends of people in the social networks of the student investigators (but no own friends or relatives). They had to be over 50 years old; with no neurological condition, cognitive decline or mental health problems (based on self-report); speak English fluently; and living independently in the community.

Procedures and measures

The study was approved by the relevant National Health Service (NHS) local research ethics

committees (for participants with stroke) and by the Language and Communication Sciences proportionate review committee of the School of Health Sciences, City University London (for healthy participants). Interviews with participants with stroke were carried out by aphasia-specialist speech and language therapists, who supported comprehension and expression using total communication techniques as appropriate. When necessary, for example if a participant became tired, the interview was completed over more than one session. Interviews with healthy participants were carried out by final year student Speech and Language Therapists. Participants were interviewed at a setting of their choice (e.g. home, local café, community group meeting place).

Participants with stroke completed a range of measures as part of the larger study at three time points (while still in hospital within two weeks of stroke, three months, and six months post stroke). Their data on the Stroke Social Network Scale (SSNS) (Northcott & Hilari, 2013) and Medical Outcomes Study Social Support Survey (SSS) (Sherbourne & Stewart, 1991) in the chronic stage (i.e. six months post stroke) will be reported here. Healthy participants completed: a short case history on demographic variables and health, to ensure they met the eligibility criteria, the SSNS and the SSS.

The SSNS comprises 19 items that assess number of network members (e.g. ‘how many close relatives do you have?’), frequency of contact (e.g. ‘in the past month, how often did you see your children?’), with six response options ranging from ‘not at all’ to ‘every day’), proximity (e.g. ‘how many of your close friends live nearby?’), with four response options ranging from ‘none of them’ to ‘all of them’), and satisfaction (e.g. ‘How satisfied are you overall with your social network?’ with six response options ranging from ‘very dissatisfied’ to ‘very satisfied’). The items fall into five domains: satisfaction with social network, children, relatives, friends, and groups. The scale yields an overall social network

score and five domain scores. Scores range 0-100 and higher scores are indicative of better social networks. The SSNS has been tested with people with stroke, including people with aphasia, with strong evidence for the scale's internal consistency ($\alpha = .85$); convergent ($r = .34$; $r = .53$), discriminant ($r = -.10$; $r = -.19$) and known groups validity (differentiated between those with high versus low perceived social support, $p = .01$). Moderate changes from two weeks to six months supported responsiveness ($d = .32$; standardised response mean (SRM) = .46) (Northcott & Hilari, 2013).

The SSS assesses the perceived availability of functional social support. It comprises 19 items that explore five functions of support: tangible; emotional; informational; positive social interaction (or social companionship); and affectionate support. The questions ask whether a specific type of support is perceived as available to a person if they need it, and response options range from 1 'none of the time' to 5 'all of the time'. Affectionate support (involving expressions of love and affection) is included as a separate scale as the authors hypothesised this type of support may be beneficial to the chronically ill. Due to overlap between the emotional support and informational support items, the authors combined these into one support domain. Thus the measure gives five scores: four for the domains and an overall perceived social support score. The SSS was psychometrically tested with people with chronic conditions (e.g. hypertension, diabetes) and demonstrated good internal consistency ($\alpha = .91 - .97$), stability over time ($r = .72 - .78$) and validity (Sherbourne & Stewart, 1991); and has been used with people with aphasia (Hilari & Northcott, 2006; Hilari, Wiggins, Roy, Byng, & Smith, 2003). In order to facilitate people with aphasia, the presentation of the scale was adjusted (e.g. few items per page; key words emboldened, large font). Wording of the items was not changed, however, to avoid affecting the psychometric properties of the scale.

Data analysis

Descriptive statistics were used to describe participants and summarise their social networks and perceived social support. One-way independent groups ANOVAs were used to compare participants six months post stroke without aphasia, with aphasia, and healthy older adults on social networks (SSSN, six scores) and social support (SSS, five scores). To minimise multiple comparisons we explored overall SSNS and SSS scores first. Subdomain scores were only explored where significant differences were found in overall scale scores. To ensure that any found differences between the three groups did not reflect non-stroke related differences (e.g. differences in recruitment strategy), where relevant, we also compared the healthy older adults with data collected from the stroke participants while they were still in hospital after their stroke, where they reported on their pre-morbid patterns of social network and support. This approach resulted in 12 comparisons for the SSNS (six for when participants with stroke were six months post stroke and six for when they were still in hospital) and one comparison for the SSS. Bonferroni corrections were applied for multiple comparisons. Data are reported at standard levels of significance ($p < .05$) first and then with Bonferroni corrections applied ($0.05/13$, $p < .004$). All data analyses were performed with SPSS v.22.

Results

One hundred and six healthy participants and 71 participants with stroke, including 11 (16%) with aphasia took part in the study. Table 1 details their characteristics. The majority of the healthy participants were women (59%), whereas the majority of the stroke participants were men (55% of those without and 64% of those with aphasia). Healthy participants ranged in

age 50-91 with a mean age of 62.8 ($SD = 9.5$). Participants with stroke ranged in age from 18-91, with a mean age of 69.8 ($SD = 14.3$) for those without aphasia and 66.5 ($SD = 13.7$) for those with aphasia. In all groups the majority were married / had partner (67% in healthy, 55% in stroke participants without aphasia, and 46% in those with aphasia) and lived with someone (67%, 59% and 54.5% respectively)

[Table 1 about here]

Tables two and three present participant scores on the SSNS and the SSS. On the SSNS, participants with aphasia scored lowest on the overall score and all the subdomains (12.1 – 76.9) and healthy participants scored highest (41.1 – 84.8). A one-way independent groups ANOVA showed there was a significant difference between the three groups on the overall SSNS score $F(2, 174) = 11.5, p < .001, \eta_p^2 = .89$. Pairwise comparisons showed there was a difference between healthy participants and those with stroke ($p = .013$), between those with stroke and those with aphasia ($p = .018$), and a significant difference between healthy participants and those with aphasia ($p < .001$).

Since the overall SNSS score was significantly different between the three groups, we also explored the subdomain scores (five subdomains). There was a significant difference in the Friends domain of the SSNS, $F(2, 174) = 6.48, p = .002, \eta_p^2 = .07$. In pairwise comparisons, the scores of people with stroke were higher than those with aphasia ($p = .032$), and those of healthy participants were significantly higher than those of people with aphasia ($p = .002$). There was also a significant difference in the Groups domain of the SSNS, $F(2, 174) = 10.32, p < .001, \eta_p^2 = .11$. In pairwise comparisons, scores were significantly different between healthy participants and those with stroke ($p = .003$) and healthy participants and

those with aphasia ($p = .001$). There were no significant differences in the Children, Relatives and Satisfaction with network domains of the SSNS.

We also compared the healthy older adults' SSNS scores with the pre-morbid SSNS scores of the stroke participants with and without aphasia, where at two weeks post stroke they were asked to reflect on their life in the month prior to the stroke (six comparisons). There were no significant differences in any of the SSNS scores, with the exception of the Groups domain [$F(2, 174) = 5.89, p = .003$; in pairwise comparisons, healthy vs stroke participants $p = .081$; healthy vs participants with aphasia $p = .008$]. Thus even before the stroke, the participants with stroke and aphasia were less involved in group activity than the healthy older adults. We repeated the comparison of the Groups domain between the three groups at six months post-stroke with the baseline Groups score as a covariate: $F(2, 173) = 4.98, p = .008, \eta_p^2 = .054$.

~~After applying a Bonferroni correction for multiple comparisons, the p value for significance was set at $< .004$. For participants six months post stroke without aphasia, with aphasia, and healthy older adults, the difference in the overall SSNS scores remained significant ($p < .001$); with those with aphasia scoring significantly lower than the healthy participants ($p < .001$). The difference between participants with aphasia and healthy participants on the Friends domain of the SSNS also remained significant ($p = .002$).~~

[Table 2 about here]

Table 3 presents participant scores on the SSS. The mean scores of healthy participants ranged 4.0 – 4.3, of those with aphasia 3.7 – 4.0, and of those with stroke 3.6 – 3.9. There were no significant differences between participants with aphasia, participants with stroke and healthy participants on their overall SSS score $F(2, 173) = 1.73$, ns.

[Table 3 about here]

Discussion

We compared the social networks and perceived functional support of 106 healthy older adults with 71 people who were six months post stroke, 11 of whom had aphasia. The healthy older adults had significantly stronger social networks ($p < .001$) than stroke participants on the overall measure of social network, with those with aphasia scoring significantly lower than the healthy participants ($p < .001$). People with aphasia also had significantly lower scores on the Friends subdomain of the social network measure ($p = .002$). Overall scores of perceived social support did not vary significantly between the three groups.

Previous studies have compared aspects of social network functioning in healthy controls and people post-stroke and found that people with stroke fare worse (Astrom et al., 1992; Cruice et al., 2006; Ross & Wertz, 2003). This was the first study to use a complex measure of social network functioning to compare healthy older adults with stroke participants with and without aphasia. The measure included concepts such as size, frequency of contact, network composition, proximity and satisfaction with network (Northcott & Hilari, 2013). That stroke participants had significantly worse overall social network functioning underlines the vulnerability of social networks following a stroke. Of interest is

that the largest differences were between healthy people and ~~appears to be driven by~~ those with aphasia.

In terms of which aspects of the social network differentiated the three groups, there was a significant difference in the Friends domain between people with aphasia and healthy older adults. The Friends domain included items on number of close friends, frequency of remote and face to face contact and proximity. Having less contact with friends is a trend consistently found in the aphasia literature (Dalemans et al., 2010; Hilari & Northcott, 2006; Parr, 2007; Vickers, 2010). A meta-ethnographic synthesis of qualitative studies exploring social support post stroke found that communication difficulties was a major reason for friendship loss (Northcott, Moss, et al., 2015). Aphasia made it harder to have in-depth discussions, gossip, make jokes, join in conversations, and friends and acquaintances were described as feeling awkward because of the aphasia (Northcott, Moss, et al., 2015). Findings from the present study underline that post-stroke friendship loss is more pronounced for those with aphasia than other stroke survivors, and clearly differentiates this group from healthy older adults.

There was also a significant difference between stroke participants with and without aphasia and the healthy older adults in the Groups domain. This result, however, should be interpreted cautiously. In fact, even prior to the stroke, the Groups domain was significantly weaker in the stroke survivors than the healthy older adults, suggesting that at least some of the difference relates to non-stroke factors. One factor may be the manner of recruitment. The recruitment strategy of healthy older adults relied at least partially on visiting community groups and working through organisations such as the University of the Third Age, which provides educational, creative and leisure opportunities for retired people in the UK.

Recruiting via groups may have skewed the healthy older sample so that the Groups domain was particularly strong.

Other social network domains were not found to be significantly different between the three groups. This finding is in line with other studies that have found contact with children to remain stable post stroke (Hilari & Northcott, 2006) or comparable with controls (Astrom et al., 1992). Contact with the wider family (Relatives domain) was also not significantly different between the three groups, suggesting the overall difference in social network functioning in this sample was primarily driven by changes in non-kin contact.

Turning to perceived functional support, there was no significant difference on the overall measure between the three groups. Some caution in interpreting this result should perhaps be exercised. Firstly, we did not analyse support functions separately (e.g. emotional support; tangible support; social companionship support): it may be that discrete support functions are affected differently by the stroke. Secondly, the study may have been underpowered to detect a significant finding. Nonetheless, as reported elsewhere, the stroke participants' perceived functional support did not differ significantly from pre-morbid levels (Northcott, Marshall, & Hilari, in press). Further, other stroke studies have found that perceived functional support remains relatively stable across time post onset (King, Shade-Zeldow, Carlson, Feldman, & Philip, 2002; Tsouna-Hadjis, Vemmos, Zakopoulos, & Stamatelopoulos, 2000). Thus despite the well-documented strains placed on intimate relationship following a stroke (Pallesen, 2014; Winkler, Bedford, Northcott, & Hilari, 2014) this construct may be relatively stable, which is the pattern found in the general population (Sarason et al., 1986). It has been hypothesised that perceived functional support may in fact reflect attachment style: high perceived support related to secure attachment; low perceived

support related to anxious or avoidant attachment (Sarason et al., 1986). As such, perceived functional support may reflect the quality of long-standing intimate relationships.

Study strengths and limitations

A strength of the study was that it used psychometrically sound and complex measures of different aspects of social relationships: perceived functional support and social networks. It is the first study to compare directly these different dimensions of social support in healthy older adults and stroke survivors with and without aphasia. Use of these measures allowed for a detailed exploration of specific social network subdomains that most clearly differentiate between the three groups. A further strength was that the stroke sample included people with aphasia, achieved through careful choice of measures that are accessible for this population, and through procedures which facilitated their inclusion e.g. all interviews carried out face to face with an aphasia-specialist Speech and Language Therapist. Nonetheless, only 16% of the stroke sample had aphasia: larger numbers would have provided stronger evidence. Further, those with the most severe receptive aphasia were not included. Yet severity of aphasia has been found to significantly predict time spent out of the house (Code, 2003); and involvement in social activities (Cruice, Worrall, Hickson, & Murison, 2003). It is therefore possible that had the most severely language-disabled individuals been included, more differences between the groups would have been observed.

A weakness of the study is that the healthy older adults who participated in this study were on average younger than the stroke participants and more likely to be married and female. Since age, gender and marital status are factors known to influence how a person views their social relationships (Antonucci & Akiyama, 1987; Hilari & Northcott, 2006; Wenger, 1994), this may have influenced findings. A further factor was the way in which the

healthy older adults were recruited. Through relying on the extended social networks of the student investigators, and recruiting via groups such as the University of the Third Age, the healthy older adults may have had a higher socio-economic status and educational background than the stroke participants: these factors were not controlled for. Still, it is reassuring that we were able to compare the pre-morbid social networks and social support of the stroke participants with the healthy older adults in order to assess whether non-stroke related factors could be responsible for differences between the groups. In fact, no differences were found between the groups pre-morbidly, excepting the Groups domain of the SSNS. This lends robustness to the finding that stroke and aphasia differentially affect social network functioning and social support.

Clinical Implications

First stated in 1948, the World Health Organisation's definition of health is that it is a state 'of complete physical, mental and social well-being and not merely the absence of disease or infirmity.' Thus consideration of the social context in which people experience health states has become important in healthcare provision. The biopsychosocial model of health proposed in 2001 by WHO (WHO-ICF) places emphasis on participation as 'involvement in life situations' (World Health Organisation, 2001). Participation, along with consideration of social relationships and social roles, has been incorporated into stroke guidelines as goals of rehabilitation (Department of Health, 2007; Intercollegiate Stroke Working Party, 2012). It should therefore be of concern that overall social network functioning, particularly contact with friends, is significantly worse for those with stroke and aphasia than the healthy older population.

There is a particularly compelling case to consider the impact of aphasia on

friendships. Friends typically belong to the same age group, are chosen, and the relationship tends to be reciprocal and based on shared values, interests and activities (Hartup & Stevens, 1999). For older people, friends have been found to be an important source of companionship support (Wenger, 1994). Lack of social companionship support has been linked to significantly poorer health-related quality of life in those with chronic aphasia (Hilari & Northcott, 2006). Establishing or preserving meaningful social relationships has been identified as key to 'living successfully' with aphasia: the role of social companionship is highlighted in Brown, Davidson, Worrall, and Howe (2013), where people with aphasia state the importance of spending time with friends, engaging in leisure pursuits, laughter and 'making a good time'. Davidson, Howe, Worrall, Hickson, and Togher (2008) also found that engaging with friends through humour and sharing topics of mutual interest was an important component of feeling connected and finding communication satisfying.

In supporting the social well-being of someone who has had a stroke various strategies are described in the literature. Offering therapy in a social context (van der Gaag et al., 2005), and peer support, either one to one or via groups, has been described as conferring many advantages, such as mutual support, enjoyment, and meeting others 'in the same boat' which may help to normalise the stroke experience (Brown et al., 2013; Northcott, Moss, et al., 2015). A person's social network may also be better maintained if important network members are included in the therapy process, for example, if close friends are given some support in how to communicate with those who have aphasia when they first visit in hospital. Further, supporting family members may enhance the quality of support that they can give to the person with stroke. Working with internal barriers to social participation, such as depression, and enabling a person to adjust to their post stroke life through therapy approaches such as solution focused brief therapy (Northcott, Burns, Simpson, & Hilari,

2015) may also be beneficial. More broadly, ensuring that the wider society is accessible to stroke survivors through increased public awareness, education or legislation may also enable stroke survivors to take on more active social roles in their communities. In order to target resources, more routine screening of social well-being and social isolation is likely to be useful, including in the chronic stage post stroke.

In terms of future directions there has been little research exploring how to enable people with stroke to maintain their pre-stroke friendships, nor is it known what value such interventions would hold either to the friend or stroke survivor. Further research could also explore at what stage post stroke it is most useful to provide interventions aimed at opening up avenues of social companionship. Finally, further studies with larger samples of people with aphasia would provide stronger evidence of how the stroke affects their social relationships compared to other stroke survivors and age-matched controls.

Conclusion

This study compared healthy older adults with people six months post stroke on measures of perceived social support and social network. One hundred and six healthy older adults, 60 stroke survivors without aphasia, and 11 stroke survivors with aphasia participated completing the same measures. The healthy older adults had significantly stronger social networks than people with aphasia. Friendships appear to be particularly affected by stroke and aphasia. There was no significant difference between the three groups in terms of overall perceived functional support. Stroke services should consider the social impact of stroke, including ways to support stroke survivors in maintaining diverse and satisfying social networks. Aphasia appears to pose significant challenges, and this subgroup of the stroke population may benefit from targeted support.

Acknowledgements

The authors would like to thank all the participants as well as the stroke teams of St Mary's Hospital and the Royal Free Hospital in London. We would also like to thank Charlotte Bower, Shima Yazdi, Lorraine Omeku, Suneet Cheema, Natalie Lower, Samantha Baddick and Dorothy Young who all contributed to the data collection for this project.

Table 1. *Participant characteristics.*

Variable	Respondent n (%)		
	Healthy participants n = 106	Participants with stroke (no aphasia) n = 60	Participants with aphasia n=11
Gender			
Female	63 (59%)	27 (45%)	4 (36%)
Male	43 (41%)	33 (55%)	7 (64%)
Age			
Mean [SD]	62.8 [9.5]	69.8 [14.3]	66.5 [13.7]
Range	50 - 91	18 – 91	46 – 85
Marital status			
Single	10 (9%)	12 (20%)	2 (18%)
Married/ has partner	71 (67%)	33 (55%)	5 (46%)
Divorced or widowed	25 (24%)	15 (25%)	4 (36%)
Ethnic group	<i>n=80</i>		
White British	50 (62%)	44 (73%)	8 (73%)
Other British	30 (38%)	16 (27%)	3 (27%)
Living arrangements	<i>n=59</i>		
Lives alone	35 (33%)	24 (41%)	5 (45.5%)
Lives with someone	71 (67%)	35 (59%)	6 (54.5%)
Stroke severity- NIH Stroke Scale	<i>n=10</i>		
Mean [SD]	Not applicable	5.68 [4.3]	9.1 [5.4]
Range		0-17	4-21
Stroke type			
Ischaemic	Not applicable	52 (87%)	10 (91%)
Haemorrhagic		8 (13%)	1 (9%)

Table 2. *Stroke Social Network Scale: descriptive statistics for healthy and stroke participants with and without aphasia.*

Stroke Social Network Scale (scale range of scores = 0-100)			
Overall scale	Healthy participants (n=106)	Participants with stroke (no aphasia) (n=60)	Participants with aphasia (n=11)
Social Network***			
Mean (SD)	64.7 (11.8) ***	58.6 (14.1)	46.7 (18.9) ***
Range	15.5 – 87.0	24.9 – 85.2	10.3 – 66.6
Subdomains			
Satisfaction			
Mean (SD)	84.8 (13.9)	83.6 (16.7)	76.9 (30.0)
Range	24 - 100	16.7 – 100	6.7 - 100
Children			
Mean (SD)	68.8 (28.2)	60.3 (35.1)	50.3 (28.7)
Range	0 - 100	0 – 100	0 – 87.5
Relatives			
Mean	41.1 (22.1)	37.9 (28.0)	30.5 (35.9)
Range	0 – 93.3	0 – 93.3	0 – 93.3
Friends ***			
Mean (SD)	53.1 (20.5) ***	47.0 (25.0)	27.4 (38.8) ***
Range	0 - 100	0 – 89.3	0 - 95
Groups ***			
Mean (SD)	53.4 (36.8)***	34.4 (34.4)***	12.1 (27.0)***
Range	0 - 100	0 – 100	0 – 66.7

* : $p < .05$

*** : $p < .004$

Table 3. *Perceived Social Support Scale: descriptive statistics for healthy and stroke participants with and without aphasia.*

Social Support Scale (scale range of scores = 1.0-5.0)			
Overall scale	Healthy participants (n=106)	Participants with stroke (no aphasia) (n=60)	Participants with aphasia (n=10)
Social Support			
Mean (SD)	4.1 (0.9)	3.8 (1.1)	3.8 (0.8)
Range	1.4 – 5.0	1.2 – 5.0	2.5 – 5.0
Subdomains			
Tangible			
Mean (SD)	4.0 (1.1)	3.9 (1.2)	4.0 (1.1)
Range	1.0 – 5.0	1.3 – 5.0	2.0 – 5.0
Affectionate			
Mean	4.3 (1.0)	3.9 (1.3)	4.0 (0.8)
Range	1.0 – 5.0	1.0 – 5.0	2.7 – 5.0
Social Companionship			
Mean (SD)	4.1 (0.9)	3.6 (1.3)	3.9 (0.9)
Range	1.3 – 5.0	1.0 – 5.0	2.7 – 5.0
Emotional / Informational			
Mean (SD)	4.1 (0.9)	3.9 (1.2)	3.7 (0.9)
Range	1.2 – 5.0	1.0 – 5.0	2.3 – 5.0

References

- Antonucci, T. C., & Akiyama, H. (1987). Social networks in adult life and a preliminary examination of the convoy model. [Research Support, Non-U.S. Gov't Research Support, U.S. Gov't, Non-P.H.S. Research Support, U.S. Gov't, P.H.S.]. *J Gerontol*, *42*(5), 519-527.
- Astrom, M., Adolfsson, R., Asplund, K., & Astrom, T. (1992). Life before and after stroke. Living conditions and life satisfaction in relation to a general elderly population. *Cerebrovasc Dis*, *2*, 28-34.
- Berkman, L. F., Glass, T., Brissette, I., & Seeman, T. E. (2000). From social integration to health: Durkheim in the new millennium. [Review]. *Soc Sci Med*, *51*(6), 843-857.
- Boden-Albala, B., Litwak, E., Elkind, M. S., Rundek, T., & Sacco, R. L. (2005). Social isolation and outcomes post stroke. *Neurology*, *64*(11), 1888-1892. doi: 10.1212/01.WNL.0000163510.79351.AF
- Bowling, A. (1997). *Measuring health. A review of quality of life measurement scales*. Buckingham UK: Open University Press.
- 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
- Code, C. (2003). The quantity of life for people with chronic aphasia. *Neuropsychol Rehabil*, *13*(3), 379-390. doi: 10.1080/09602010244000255
- 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.
- Cruice, M., Worrall, L., Hickson, L., & Murison, R. (2003). Finding a focus for quality of life with aphasia: social and emotional health and psychological well-being. *Aphasiology*, *17*(4), 333-353.
- Dalemans, R. J., de Witte, L., Wade, D., & van den Heuvel, W. (2010). Social participation through the eyes of people with aphasia. *Int J Lang Commun Disord*, *45*(5), 537-550. doi: 10.3109/13682820903223633
- Davidson, B., Howe, T., Worrall, L., Hickson, L., & Togher, L. (2008). Social participation for older people with aphasia: the impact of communication disability on friendships. *Top Stroke Rehabil*, *15*(4), 325-340. doi: 10.1310/tsr1504-325
- Department of Health. (2007). National Stroke Strategy. Accessed in, http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_081062.
- Ditzen, B., & Heinrichs, M. (2013). Psychobiology of social support: The social dimension of stress buffering. *Restor Neurol Neurosci*. doi: 10.3233/RNN-139008

- 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. [Research Support, Non-U.S. Gov't]. *Int Rehabil Med*, 8(4), 166-170.
- 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.
- Haber, M. G., Cohen, J. L., Lucas, T., & Baltes, B. B. (2007). The relationship between self-reported received and perceived social support: a meta-analytic review. [Meta-Analysis Review]. *Am J Community Psychol*, 39(1-2), 133-144. doi: 10.1007/s10464-007-9100-9
- Hartup, W., & Stevens, N. (1999). Friendships and adaptation across the life span. *Current Directions in Psychological Science*, 8(3), 76-79.
- Haun, J., Rittman, M. R., & Sberna, M. (2008). The continuum of connectedness and social isolation during post stroke recovery. *Journal of Aging Studies*, 22, 54-64.
- Hilari, K. (2011). The impact of stroke: are people with aphasia different to those without? [Comparative Study]. *Disabil Rehabil*, 33(3), 211-218. doi: 10.3109/09638288.2010.508829
- Hilari, K., & Northcott, S. (2006). Social support in people with chronic aphasia. *Aphasiology*, 20, 17-36.
- Hilari, K., Northcott, S., Roy, P., Marshall, J., Wiggins, R. D., Chataway, J., & Ames, D. (2010). Psychological distress after stroke and aphasia: the first six months. [Research Support, Non-U.S. Gov't]. *Clin Rehabil*, 24(2), 181-190. doi: 10.1177/0269215509346090
- Hilari, K., Wiggins, R. D., Roy, P., Byng, S., & Smith, S. C. (2003). Predictors of health-related quality of life (HRQL) in people with chronic aphasia. *Aphasiology*, 17(4), 365-381.
- Holt-Lunstad, J., & Smith, T. (2012). Social relationships and mortality. *Social and personality psychology*, 6(1), 41-53.
- Intercollegiate Stroke Working Party. (2012). *National clinical guideline for stroke*. London: Royal College of Physicians.
- King, R. B., Shade-Zeldow, Y., Carlson, C. E., Feldman, J. L., & Philip, M. (2002). Adaptation to stroke: a longitudinal study of depressive symptoms, physical health, and coping process. *Top Stroke Rehabil*, 9(1), 46-66.
- Lee, M. K., Park, S., Lee, E. S., Ro, J., Kang, H. S., Shin, K. H., . . . Yun, Y. H. (2011). Social support and depressive mood 1 year after diagnosis of breast cancer compared with the general female population: a prospective cohort study. [Research Support, Non-U.S. Gov't]. *Support Care Cancer*, 19(9), 1379-1392. doi: 10.1007/s00520-010-0960-4
- Litwin, H. (2001). Social network type and morale in old age. *Gerontologist*, 41(4), 516-524.
- Moyer, A., & Salovey, P. (1999). Predictors of social support and psychological distress in women with breast cancer. *J Health Psychol*, 4(2), 177-191. doi: 10.1177/135910539900400212

- Northcott, S., Burns, K., Simpson, A., & Hilari, K. (2015). 'Living with aphasia the best way I can': an evaluation of a feasibility study exploring solution focused brief therapy for people with aphasia. *Folia Phoniatrica et Logopaedica*, 67(3).
- Northcott, S., & Hilari, K. (2011). Why do people lose their friends after a stroke? [Research Support, Non-U.S. Gov't]. *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. [Research Support, Non-U.S. Gov't]. *Clin Rehabil*, 27(9), 823-833. doi: 10.1177/0269215513479388
- Northcott, S., Marshall, J., & Hilari, K. (in press). What factors predict who will have a strong social network following a stroke? *Journal of Speech, Language and Hearing Research*.
- 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
- Pallesen, H. (2014). Body, coping and self-identity. A qualitative 5-year follow-up study of stroke. [Research Support, Non-U.S. Gov't]. *Disabil Rehabil*, 36(3), 232-241. doi: 10.3109/09638288.2013.788217
- Parr, S. (2007). Living with severe aphasia: tracking social exclusion. *Aphasiology*, 21(1), 98-123.
- Pinquart, M., & Sorensen, S. (2000). Influences of socioeconomic status, social network, and competence on subjective well-being in later life: a meta-analysis. [Meta-Analysis]. *Psychol Aging*, 15(2), 187-224.
- Ross, K., & Wertz, R. (2003). Quality of life with and without aphasia. *Aphasiology*, 17(4), 355-364.
- Sarason, B. R., Sarason, I. G., & Shearin, E. N. (1986). Social support as an individual difference variable: its stability, origins, and relational aspects. *J Pers Soc Psychol*, 50, 845-855.
- Sherbourne, C. D., & Stewart, A. L. (1991). The MOS social support survey. [Research Support, Non-U.S. Gov't]. *Soc Sci Med*, 32(6), 705-714.
- Taylor, M. G., & Lynch, S. M. (2004). Trajectories of impairment, social support, and depressive symptoms in later life. [Research Support, U.S. Gov't, P.H.S.]. *J Gerontol B Psychol Sci Soc Sci*, 59(4), S238-246.
- 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
- Tsouna-Hadjis, E., Vemmos, K. N., Zakopoulos, N., & Stamatelopoulos, S. (2000). First-stroke recovery process: the role of family social support. *Arch Phys Med Rehabil*, 81(7), 881-887. doi: 10.1053/apmr.2000.4435
- 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. [Research Support, Non-U.S. Gov't]. *Clin Rehabil*, 19(4), 372-380.

- Vickers, C. (2010). Social networks after the onset of aphasia: the impact of aphasia group attendance. *Aphasiology*, 24(6-8), 902-913.
- 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.
- World Health Organisation. (2001). International classification for functioning, disability and health (ICF). Geneva, Switzerland: World Health Organisation.