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## **Aphasia blog talk: how does stroke and aphasia affect a person's social relationships?**

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## **Aphasia blog talk: how does stroke and aphasia affect a person's social relationships?**

### **Abstract**

**Background:** Stroke and aphasia can negatively affect a person's ability to maintain healthy social relationships, both within the family and also with friends and the wider network. To date this has been explored predominantly through qualitative interviews and questionnaires. Blogs written by people with aphasia constitute a novel source of data, comprised of people's own voices on issues that are of concern to them.

**Aims:** to explore the impact of stroke and aphasia on a person's relationships with family, friends and the wider network through analysing blogs written by people with aphasia.

**Methods:** Blog search engines were used to identify blogs sustained by a sole author who had aphasia following a stroke, and which reflected on their social network. The data was analysed qualitatively using Framework analysis.

**Outcomes and results:** The systematic search resulted in 10 relevant blogs. Participants were aged between 26 to 69 years old, lived in the community, were at least one year post stroke, and included six women and four men. Aphasia was a consistent thread running through the blogs affecting conversations with all parts of a person's network, and impacting on participants' sense of self. They found it more difficult to take part in family activities, and described higher degrees of dependence and changed family dynamics. Contact with friends was reduced, partly due to communication and physical difficulties. While some participants became motivated to become members of groups post stroke, contact with the wider network sometimes diminished, in part because of loss of work and community activities. An additional factor impacting on social relationships were other people's positive or negative reactions towards the person with aphasia. Finally, the blogs reflected on the importance of support they had received, both from close family and also the wider community.

**Conclusions:** This study found that social relationships played a crucial role in people's lives following a stroke and aphasia. Nonetheless, family relationships, friendships and social exchanges within the wider social network were all substantially affected. Exploring this area through online narratives offered a rich and highly authentic source of data. The findings

suggest that clinicians should incorporate social approaches in rehabilitation and consider ways to foster the maintenance of social networks. The use of social media by people with aphasia should be further explored, both as a therapeutic outlet and also as a way for people with aphasia to feel connected to a wider community.

**Keywords:** Aphasia, blogs, impact, relationships, psychosocial outcomes

## **Introduction**

The impact of having a stroke with resulting aphasia on social relationships can be considerable. Studies have found that following a stroke, people take part in fewer social activities, contact with friends and the wider network is vulnerable, and increased strain is placed on the family unit (Astrom, Adolfsson, Asplund, & Astrom, 1992; King, Shade-Zeldow, Carlson, Feldman, & Philip, 2002; Northcott & Hilari, 2011). Those with aphasia may be particularly likely to experience negative social consequences (Dalemans, de Witte, Wade, & van den Heuvel, 2010; Vickers, 2010). Analysis of blog posts written by those with aphasia may provide an ‘insider’ perspective on how these social changes are perceived and the consequences for everyday life.

Aphasia can affect all aspects of communication and can thus potentially have a profound impact on how a person experiences both family life and interaction within the wider network. There is evidence that those with aphasia experience a constriction of their social network (Parr, 2007; Vickers, 2010), and have smaller networks than age-matched controls (Cruice, Worrall, & Hickson, 2006). There is also evidence that those with aphasia take part in fewer social activities than controls (Cruice et al., 2006) and see their friends, relatives and social acquaintances less frequently than prior to the stroke (Brown, Davidson, Worrall, & Howe, 2013; Vickers, 2010). Hilari and Northcott (2006) explored the social experiences of 83 people with chronic aphasia, and found that 64% reported that they saw their friends less than prior to the stroke and 30% reported having no close friends at all. In a study comparing the experiences of those with and without aphasia at around one year post stroke, it was documented that while all stroke survivors were at risk of losing contact with friends, aphasia posed specific challenges (Northcott & Hilari, 2011). In particular, those with aphasia experienced the most hurtful negative responses from others, and were more likely to report feeling abandoned or rejected by pre-stroke friends. The consequence of this reduction in the social network is that many describe feelings of loneliness and exclusion (Dalemans et al., 2010; Parr, 2007).

Contact with family members has been found to be more robust than contact with non-kin following stroke and aphasia (Cruice et al., 2006; Hilari & Northcott, 2006). However, there is evidence that having a stroke can cause significant deterioration in family functioning in the months following discharge from hospital (Clark & Smith, 1999; Dowswell et al., 2000; King et al., 2002). The qualitative aphasia literature also describes the disruption to the

family unit, and new tensions in the marital relationship (Hinckley, 2006; LeDorze & Brassard, 1995; Parr, Byng, & Gilpin, 1997). Distress associated with lost roles and new dependence on family members, particularly the spouse, has been well-described (Ch'ng, French, & McLean, 2008; Dowswell et al., 2000). Language difficulties have been reported to make it harder to negotiate these shifts in family dynamics, and can take away a source of comfort (Parr et al., 1997).

There is evidence that poor social support, loss of friends and reduced social participation post stroke are associated with a number of adverse psychosocial outcomes. In a recent systematic review looking at factors predictive of health-related quality of life for people with aphasia, social factors such as poor support and reduced social network were found to contribute to poor health-related quality of life in 3/4 studies (Hilari, Needle, & Harrison, 2012). A number of stroke studies have documented a significant association between depression and social factors such as loneliness and low satisfaction with social network (Hilari et al., 2010); few social contacts outside the house (Astrom, Adolfsson, & Asplund, 1993); poor family functioning (King et al., 2002); and low perceived social support (Chau et al., 2010; Townend et al., 2007).

Increasingly, the aim of healthcare interventions is 'to achieve a good quality of life' with emphasis not only on improving physical function, but also emotional and social well-being (Department of Health, 2007). The National Clinical Guidelines of the Royal College of Physicians states that: 'the goal of healthcare is to help a person integrate back into the community in the way that they want' (Intercollegiate Stroke Working Party, 2012, p. 126). It is therefore legitimate to consider the difficulties that people with aphasia face, in order to better facilitate their participation and improve their social well-being.

To date, methods used to explore the social impact of stroke and aphasia include qualitative techniques, such as in-depth interviews or ethnography, as well as self-report scales, including those specifically validated for people with aphasia, such as the Stroke and Aphasia Quality of Life Scale (Hilari et al., 2003; (Hilari et al., 2009), and the Stroke Social Network Scale (Northcott & Hilari, 2013). Published accounts written by people with aphasia have also been analysed, providing detailed 'insider' perspectives on how individuals have adapted to living with aphasia (Hinckley, 2006). A previously untapped source of rich data is self-reports on the internet. Internet blogs work as online diaries and can help researchers explore the impact of chronic illnesses (Robinson, 2001). Blogs constitute an authentic source of

information as they offer first-person narratives on issues that are of concern to an individual (Keim-Malpass et al., 2013). They may offer advantages over other forms of data collection. Firstly, they confer a degree of anonymity and potentially a 'safe' environment where people can explore feelings that may be challenging to acknowledge in a face to face interview (Fleitas, 1998). Further, blog authors can discuss the issues that are important to them, rather than those predetermined by specific questions. Finally, blogs comment on the 'here and now' of everyday living, rather than relying on retrospective reflections more typically sought during research (Seale, Charteris-Black, MacFarlane, & McPherson, 2010).

Blogs have emerged as popular in exploring people's experiences of health conditions such as HIV (Rier, 2007), cancer (Seale et al., 2010), and eating disorders (Adair, Marcoux, Williams, & Reimer, 2006). To date, however, there has been no analysis of the blogs written by people with stroke and aphasia. It is possible that such a novel dataset may provide new insights into the 'lived experience' of stroke and aphasia, and the impact aphasia has on social relationships. A careful examination of this data may thus enable clinicians and service providers to better support the person with aphasia.

This paper addresses the following research question: what is the impact of aphasia on a person's social relationships, as evidenced in their blog posts?

## **Methods**

The study is a qualitative descriptive analysis of online blogs written by people with aphasia on how having a stroke has affected their social relationships. Passive analysis was employed, thus the data gathered from the internet was analysed without researchers interacting directly with participants (Eysenbach & Till, 2001).

### **Ethical considerations**

The study was approved by the City University School of Health Sciences Research Ethics Committee. Only blogs that were publicly available were considered for inclusion in the study. As such, the material has been disseminated to a wide public. Further, blog-hosting websites specify terms and conditions which potential authors must agree to, establishing the public nature of material posted. Consequently, it has been argued that it is acceptable for researchers to analyse online narratives (Robinson, 2001; Seale et al., 2010). Nonetheless, in



this project blog authors were contacted and offered the option of opting out of the study. Contact was made with authors through email or twitter accounts, where these were provided, and otherwise through the open comment section on their blogs. Potential participants were sent an information sheet about the project which was adapted to be accessible to those with aphasia, and also a link to a short video (<http://vimeo.com/59493861>). Blog authors were informed that they could withdraw from the project at any time. Furthermore, to protect participants' privacy, pseudonyms have been used in this report. Blogs where a subscription or registration was required to access material were not considered, as authors are more likely to consider the website a private domain (Eysenbach & Till, 2001).

### **Participants and data collection**

To be included in the study blogs needed to meet the following inclusion criteria: to be written in English by one sole author who had aphasia and was over 18 years old, and to be publicly available. Only blogs which reflected on the experience of living with aphasia and its impact on social relationships were included. Group blogs, and blogs written by family or friends of the person with aphasia, were not considered.

To avoid missing relevant blogs the initial search was broad: the key words 'aphasia', 'dysphasia', 'stroke and language', and 'stroke and speech' were searched in the blog search engines 'Google blog search' and 'Technorati'. In addition, blogs were found through searching features of blog content management web systems such as Blogspot, Wordpress, Blogster and LiveJournal, using the same terms. Finally, blogs were located by following links provided on blogs already found.

The blogs located through this process were checked manually to ensure that the author had aphasia following a stroke, and that the blog included entries reflecting on the impact of stroke and aphasia on social relationships. Where blogs were still active, data was collected up to December 2012. All relevant entries in the blogs were included for analysis in the study, with no upper limit set.

### **Data analysis**

Blogs were analysed using Framework Analysis (Ritchie & Spencer, 1994). Framework is a matrix-based analytic method developed during the 1980s at the National Centre for Social Research, London. It involves a number of key stages (Ritchie, Spencer, & O'Connor, 2003). Following familiarisation with the material, a thematic index was developed from the key

issues, concepts and themes. This thematic framework was used to classify and organise data. Thus it was systematically applied to the whole dataset, such that each phrase and passage was labelled or ‘tagged’. The data was then summarised and synthesised into a matrix-based system of charts. Data for each main theme was displayed in its own chart, with every participant allocated a row, and separate subtopics allotted a column. This method allowed the researchers to compare between and across cases, facilitating rigorous and systematic analysis of emergent patterns. From the charted data, key dimensions were refined, and higher order classes developed. This process was iterative, with researchers frequently returning to the original documents to check that emerging themes were consistent with participants’ accounts. To reduce the risk of bias and improve the validity of the findings, two authors (AC and DF) were involved in all stages of analysis, and the process was overseen and discussed with the other authors (SN and KH). Further, one third of the data was indexed by two authors independently (AC and DF); there was 86% agreement, which is considered a satisfactory level (Stemler, 2004). Where interpretations differed at any stage in the analytic process, this was resolved by discussion until consensus was reached.

## **Results**

The initial search produced 77 results. Of these, the blogs of 10 people were included in the study. The remaining 67 were excluded for the following reasons: written by people who had a stroke but not aphasia ( $n = 28$ ); carers’ blogs ( $n = 15$ ); did not include material addressing the research question ( $n = 15$ ); written by multiple authors / platforms ( $n = 4$ ); single entries ( $n = 5$ ).

All 10 blog authors were contacted for consent, two via email addresses and the rest via comment boxes or online contact forms. Five people responded to give their consent and no-one opted out. The number of posts per blog ranged from 38 to 520.

### **Participant characteristics**

The participants in this project ranged in age from 29 to 69 years old (one unknown), and included six women and four men. In terms of nationality, seven blog authors were American, two British and one Turkish. All participants were either married or had a partner. Three participants were living with their spouse, four participants were living with spouse

and children, and three were living alone. There was variation in terms of physical impairments: while some were walking independently, others were using walking aids, and one was a wheelchair user. All participants had aphasia, although severity varied. Brief participant details are provided in Table One. Participant information was gathered from blog entries and online blog profiles: there was no direct contact with participants to elicit details. This means that we do not know explicitly the accuracy of the self-report; additionally, the stroke-related disabilities and co-morbidities expressed may not accurately reflect the full range of difficulties experienced.

[ table one about here ]

## **Aphasia**

The impact of aphasia was a consistent thread running through the blogs, affecting interactions with all parts of a person's network. It made it harder for a person to have in-depth conversation with family or friends, and express opinions and thoughts. The language difficulty could also make a person feel less included in conversation.

*'Conversation continues one way because of my aphasia'* (Nick)

There was also a sense of not being able to get across their message in a timely way, impacting on a person's ability to make humorous observations and jokes. This is illustrated by Laura, 48, who described a car journey with her husband, where they were listening to a radio programme:

*'One of the frustrating things about aphasia for me is the lost opportunities to make snide remarks. I'm too slow... I couldn't say it [about the radio presenter] but I wanted to say: a southern drawl is nice, but she sounds like a southerner on a big dose of tranquillizers [...]*  
*[Husband] was about to turn off the car. I was still trying to formulate a witty remark.'*  
(Laura, 48)

Participants also described finding it difficult to follow conversations, particularly where multiple conversations were taking place at once. Adam, 56 years old, discussed how hard it was to follow what was being said when several close family and friends were talking together: *'Bit of bother trying to keep track of all the conversations.'* (Adam, 56)

A prevalent theme through the blogs was that the ongoing difficulties in communicating resulted in feelings of anger, frustration and depression. As noted by Rose, 55, '*Being in a world where you can't communicate to others is hard too*'. The changes in social interaction caused by the aphasia led many participants to feel they had lost a part of their former selves. They could feel unsociable, anxious, and inclined to avoid crowds. Tom described the impact on his sense of self in no longer being able to communicate with others as he used to:

*'We have lost the use of words, and thereby a piece of ourselves. [...] For someone who used words for 40 years, it completely changes my life.'* (Tom, 67)

Yet despite the difficulties, participants also found ways to adjust to their aphasia post stroke. These included expressing gratitude to still be alive and still able to '*kiss my family, children and boyfriend*' (Beth, 42).

*'We are all different. One individual is not necessarily better than another. He or she may just be different. [...] Aphasia is not the end of the world. I am still alive and I am still me.'* (Tom, 67)

## **Impact of stroke and aphasia on social relationships**

The blogs described the everyday experience of living with aphasia. A number of core themes emerged from the analysis: the impact of the stroke and aphasia on family, friends and the wider community; support received; and responses of the social network to the aphasia.

### ***Family***

#### *Changes in activities*

Participants reported restrictions in their ability to participate in family activities, such as swimming or playing games with their children. They also described limited options in terms of places they could visit, for example, not being able to go further than the local shop. Another common theme was that activities required more time than prior to the stroke. Feeling tired when outside was another barrier. This is illustrated by Beth, 42 years old, who found it difficult to accompany her son: '*I am so tired, the fatigue is getting better, but I went*

*two college visits with my son over the weekend but I am no spring chick any longer... so these were very long days for me! [...] really tired me out.'*

Feelings of unhappiness resulted from the lack of ability to participate in family gatherings.

Adam, living with his wife, described how sad he felt when not able to visit his daughter:

*'Even though Daughter Mine only lives 6 mins away, today it's a long way to go. I'm just not strong enough to walk that far today. Still made me feel awful for not going.'*

While many of these restrictions stemmed from the stroke, some were a direct consequence of aphasia. Laura, 48, illustrated this point as she described struggling to read to her five-year-old daughter at bedtime:

*'Last week she (daughter) wanted me to read The Three Little Pigs, but it's hard to be convincing when the evil wolf sounds like this: me: "Little Pig, Little Pig, let me out!" [daughter]: "You mean, Let me in."'*

#### *Changes in family dynamics*

Feeling dependent on family members was frequently raised. Participants tended to rely on others for a number of activities of daily living, such as preparing meals, as well as for compensation of lost skills like driving and talking. This often meant that another person would have to accompany them for a significant part of the day. They could therefore feel that they were losing their independence.

*'As I'm not "allowed" out alone (could you imagine that? – I wonder what they think I'm going to do?)' (Adam, 56)*

Having to rely on others, and the loss of autonomy this represented, was described as a source of worry. Carl, 69 years old and living with his wife, explained: *'[wife] showers me Sometimes weekly. Sometimes less... These are the kinds of self-imposed problems that drive me crazy too!!'*

Participants described feeling that they were losing their role in the family. They described no longer being able to take on past responsibilities, such as carrying out household chores.

There was also the sense that however supportive a spouse was, still there was a shifting of the terms of the relationship, as discussed by Laura: *'[...] partners can share some of the*

*burdens, but we have such different journeys to make. Now almost a year has gone by, and [husband] and I are still adjusting to our new shared reality'. It could also lead to a change in the husband-wife dynamic in terms of decision making. Emily, 42, reported that she could not voice her opinion regarding an important operation due to limited expressive abilities. This forced her to leave this decision to her husband:*

*'[husband] is the physician in our family, I leave the decision to him. And thus I put him in such a difficult position [...] he has to decide about my future.'*

Parenting limitations and reduced parent-child interactions owing to communication difficulties were described. An example is Emily, living with her husband and child. Prior to the stroke, she was the one mainly responsible for her three-year old's upbringing. Post stroke, her husband became the main carer. *'Up until now, he [her son] was truly a mama's boy [...] Now [husband] is the playmate, the reader, the explain it all person'.*

### **Friendships**

Friendships emerged as an important part of people's lives. Friends were referred to with great appreciation: *'They are my rock and my true north'* (Jess, 31, talking about her friends). Nevertheless, following stroke and aphasia some participants reported difficulties in maintaining their pre-stroke friendships.

#### *Reduced contact and changed preferences*

The main trend post stroke was for participants to be in less frequent contact with friends. The reported explanations included mobility issues that made travelling difficult and difficulty using technology or phones, in part due to aphasia. An example is Adam, whose contact with his best friend reduced post stroke:

*'I've not seen him [his friend] for a year, mainly because neither of us travel well, though we've kept in touch by phone I have to admit I'm not too good with phones, so the contact has been down.'* (Adam, 56 years old)

Physical disability also made other aspects of social gatherings problematic, for example, using cutlery in a restaurant, as described by Pam, aged 29.

*‘When I’m on a date at a restaurant, I may want to order a piece of meat – steak, chicken, etc. But I don’t, because cutting meat with one hand is a pain. Miss Manners says, “Asking your date to help you cut up your dinner is bad form.”’ (Pam, 29)*

Some participants described receiving visits by friends rather than initiating visits. Reduced energy levels, tiring easily during group meetings and struggling to follow group conversations resulted in a preference for meeting friends one-to-one for some participants, as discussed by Emily, 42 years old: *‘I am not ready for larger gathering, I tire easily and when there is more than one conversation my speech suffers. So we meet one-by-one with a great many of my closest friends’.*

Aphasia confounded by environmental factors, such as background noise, could also present barriers, as discussed by Jess, 31 years old: *‘My fear is when I go out with my friends and they put on background music, or suggest a late night game of Articulate... I can rarely understand the questions, let alone reply.’*

Participants also described feeling embarrassed of their aphasia. This impacted negatively on their willingness and ability to socialise. For example Beth, whose aphasia was initially severe, avoided friends as she felt uncomfortable socialising: *‘I was embarrassed by my speech [...] I hid from friends while healing’.* Participants also described feeling nervous about socialising, and worried about other people’s reactions: *‘I am anxious. I don’t know why but I am anxious about seeing my friends. Somehow I fear that when they see me, they will feel sorry for me.’* (Emily, 42).

Over time, these responses evolved and changed, however, as shown by one participant, Beth. For Beth, as her aphasia improved, she gradually started spending more time with her friends: *‘since speaking better [...] I now actually spend “real” time with my pals.’* She described developing a new approach towards friendships: *‘I am liking more and more meeting new people’.*

### **Wider social network**

Participants’ ability to interact with the wider social network also appeared to be affected by stroke and aphasia. Wider social network in this study was conceptualised as consisting of neighbours, co-workers and community members.

### *Reduced participation*

Simple, everyday communication was often described as a struggle, and participants described times when they felt unable to take part or communicate in their community due to their aphasia. Laura, for example, described her difficulties communicating with her neighbours post stroke: *'a crowd begin to form in front of me, as if the oracle was waiting to speak. But this oracle has aphasia!'*

For some participants their aphasia meant they avoided social interaction, for example, a casual conversation with someone new in their local park. Reasons given for avoidance included difficulties talking and fear of not being understood. This is illustrated by Nick:

*'[...] staying away from people because I can't talk. I would have to explain I've had a stroke and can't speak properly [...] So I avoided folk in general.'*

Rather than go out and engage in his former hobbies, Nick described how post stroke he preferred to spend time alone.

Environmental factors, such as using public transport and bathrooms, and eating and drinking in public, were also perceived as barriers that discouraged contact with others. Adam, 56, described the difficulties he encountered when someone asked him for support in a hearing, and then suggested going out for a coffee afterwards:

*'For me going out is a carefully planned military style operation. I don't – can't go out unaccompanied. [...] We need to know exactly where the buses are and how long we would have to wait for them. [...] Don't get me going on trying to catch a bus in a wheelchair.'*

While maintaining a blog was a way for people to reflect on their experiences and potentially communicate these to others, nonetheless sustaining a blog was described as a challenge. Fatigue, struggles with typing and language hurdles could make completing entries time consuming and effortful. Completion of a single post could take from half an hour to three days.

The consequence of experiencing these every day barriers to participation was that some participants expressed feelings of frustration and anger. Pam, who was 26 when she had the



stroke, described how someone *'[...] recently asked me if I was angry. The correct answer is "Of course". [...] I have had to put my life on hold?'*

### *Work*

Going back to work was difficult for most of the blog authors in this project: post stroke only Beth and Jess were in employment. Factors which made it difficult for participants to return to work included: aphasia, fatigue, older age, epilepsy, short attention span and difficulty multi-tasking. These post stroke sequelae also made searching for a new job challenging.

*'Aphasia, fatigue and age now preclude me from working at those jobs that I loved and enjoyed.'* (Tom, 67)

For some, loss of work also entailed loss of the social contact which went with the work environment.

### *New and positive social interactions post stroke*

The onset of aphasia motivated some participants to become active members of their wider community, including participating in aphasia, stroke and religious groups, such as aphasia symposiums. Emily, 42, described how becoming a member of an aphasia group enabled her to develop new friendships: *'After just one session with her we understand that we are going to become best friends'*.

Entering the social media community, for example, through blogs, Facebook and Twitter, was another new social avenue for some. Jess, 31, viewed blogging as a fun activity during which she could be herself: *'I've learnt to just be me in a blogging sphere. It's a nice safe cyber world'*.

A factor which appeared to promote participation was the person's willingness and motivation to socialise despite their difficulties. Beth, a mother of a five year old, describes her eagerness to socialise with other parents: *'I love going to the games and I am learning to socialize with the families, which I struggle a bit [...] but I'm taking baby steps to know the [surname] parents.'*

## **Support received**

A theme which came up consistently was the different types of support family members, friends and the wider social network provided to participants, and the value this held for them.

### ***Practical support***

Family members assisted in activities of daily living, like having a shower, preparing meals, and helping the participant manage their finances. They also assisted the participant with speech and language exercises and playing word or maths games.

Friends provided help such as dropping off dinner or babysitting. There were also examples of friends becoming informed about aphasia and raising money for financial support.

*'I was invited to a regular Coffee Morning event, where they surprised me with 1000 origami cranes and a check of over \$3000'* (Emily, 42, talking about her work friends).

Another way in which friends provided practical help was in seeking specialist support. Carl discussed: *'[friend] got a psychiatrist to see me.'*

Practical support from community members was also described, such as delivering shopping free of charge or helping to shovel snow off the garden path. Help was particularly appreciated in emergency situations: Rose, 55 years old, recounted how a woman in the church aided her during a seizure: *'She put her arm around me and guided me to the hall'*.

### ***Emotional support***

Participants described how family made them feel protected and loved, provide reassurance and encouragement, and created a safe, tolerant and supportive environment for them.

*'My mom - my angel through my whole stroke survival. [...] I would not be doing so well if it was not for her'* (Beth, 42).

Friends also provided valued emotional support. Jess, 31, described her friends as her *'guiding stars'*. Pam, 29, described her friend's encouragement in the lead up to brain

surgery: *'Before I had brain surgery, my friend [name] offered to shave her head in solidarity.'*

On occasion members of the wider community also provided compassion and encouragement, for example, praying for the participant every Sunday at church. Beth also described the sensitivity of work colleagues, who gave her the space and time to do things for herself, so that *'[...] have made it possible for me to lead a positive life through my recovery.'*

## **Other people's responses to the stroke and aphasia**

### ***Responses of family members***

Positive reactions reported were being supportive and tolerant, and accepting the 'new person' with aphasia. Additionally, participants told of new family jokes inspired by their aphasia.

*'Now my family is getting some good-natured family laughs over some of my speech'* (Laura, 48).

Negative reactions from family members included lack of patience, sadness and rejection. Emily, 42, commented on the negative response of her three year-old son after the stroke. Prior to the stroke, she described how she and her son were *'inseparable'*. On returning home from hospital, however, she wrote: *'he doesn't want me in the room again. When I try to lie down he pushes me out of the bed, he clings to his dad.'* Laura described her son's sadness that she had had a stroke. When looking through old family photos, her 17-year old son remarked: *'I wish you didn't have a stroke. [...] You were more fun then.'*

### ***Responses of friends and the wider community***

Although there were many examples of positive and supportive responses, there were also some more difficult reactions described. Participants felt at times that they were being labelled as disabled, with low IQ, diminished and pitied, resulting in feelings of anger and frustration. For example, Jess described her difficulty participating in a game due to fatigue, leading others to assume she was not intelligent which she found upsetting: *'And the*

*FRUSTRATING thing is that is that people think it's because you have a low IQ, which isn't the case'. Strangers could also assume they were incompetent and unable to take part in activities. Pam discussed a stranger's assumption that she would not be able to dance due to physical difficulties: 'When I stopped, another guest said "I didn't think you would dance".'. '.*

Participants on occasion also felt ignored, overlooked or invisible to others. Adam, 56, described how people would address his carer rather than talking to him directly:

*'Have you ever come across the "Does he take sugar?" syndrome? When some ignores you, talks past you or over the top of your head to a partner or carer? One of the advantages to having a deep voice that carries, is the perverse pleasure I get from watching the shock and awe when I say quietly "No, he doesn't, one sweetener, top pocket, thank you."'. '.*

## **Discussion**

This study explored the impact of aphasia on social relationships through analysing blogs written by people with aphasia. Ten blogs were included in the study. Blog authors described changes to family life, including restrictions in their ability to participate in family activities, and a shift in family dynamics resulting in part from increased reliance on family members. Although friends were described as an important part of participants' lives, they also reported difficulties in maintaining pre-stroke friendships. Mobility issues, fatigue, difficulty using the phone and embarrassment of their aphasia were all cited as reasons. Reduced participation within the wider social network was also reported. However, many participants also became involved with stroke and aphasia groups, as well as entering the social media community, in some cases for the first time. The value of emotional and practical support was also described.

The impact of aphasia on the person's sense of self and all relationships was a persistent theme running through the blogs. This study did not systematically explore identity issues, but it was noted that participants felt that had lost a part of their former selves. The literature suggests that identity is mediated through social interactions (Shadden, 2005) and in the blogs it was evident that social interactions were profoundly affected: from the difficulty of keeping track of fast moving conversations with family or friends, to the frustration of struggling to communicate in everyday situations, to the distress at no longer being the '*explain it all*' person to their young child. The day to day interactions described in blogs, where small

details of conversation could be precisely described sometimes hours after the event, underline how everyday life is laced with communication hurdles for people with aphasia, adding to the literature documenting the impact of language difficulties on social relationships (Brown, Worrall, Davidson, & Howe, 2010; Parr et al., 1997).

Consistent with previous research, stroke and aphasia were found to impact on a person's family life, in part through increased dependence. Dowswell et al. (2000) and Parr et al. (1997) also describe the shifts in family dynamics caused by a person losing previously valued roles, and the distress this could cause. Reduced ability to participate in family activities, such as family gatherings or taking the children swimming, were reported: inability to resume previously enjoyed activities has been found to be detrimental for people with aphasia (Cruice, 2010). The blogs did not, however, describe marital break down, nor distress at feeling a burden to their family, as has been found in other studies (Dowswell et al., 2000; Hinckley, 2006). This could reflect the public nature of posting material on a blog, or the lack of opportunity for probing in this research design. It may also be that for this sample these issues were not a concern: it could be that those with aphasia with supportive families may have felt more confident to initiate and maintain a blog.

In terms of friendships and the wider network, the main trend was for people to be in less frequent contact with others, which mirrors previous work in this area (Dalemans et al., 2010; Davidson, Howe, Worrall, Hickson, & Togher, 2008; Hilari & Northcott, 2006). The type of contact also appeared to change: visits appeared more likely to take place at the blogger's home; making visits to others was less frequently described, a finding replicated by Davidson et al. (2008). In part, this reflected the difficulty some participants experienced in leaving the house on their own. For those who did meet their friends outdoors, a number of factors negatively affected the experience, including difficulty negotiating public transport, mobility issues, impaired fine motor skills, and environmental barriers, such as background noise, consistent with previous qualitative research (Dalemans et al., 2010; Haun, Rittman, & Sberna, 2008; Howe, Worrall, & Hickson, 2008; Sumathipala, Radcliffe, Sadler, Wolfe, & McKevitt, 2012). The longitudinal nature of this qualitative data set meant it was possible to observe changes in friendships over time. In particular for one participant there was a movement from withdrawal to taking '*baby steps*' towards spending more time with friends and acquaintances. This evolution of social identity may link to models of grief and loss,

which suggest successful adjustment may encompass a gradual shift from focusing on grief, to 'restitution', or a rebuilding of connections and identity (Parkes, 1971; Stroebe & Schut, 1999).

Another theme that emerged was the impact of fatigue on social well-being post stroke. Fatigue not only limited the family activities a person could take part in but also impacted negatively on a person's capacity to maintain friendships and contact with a wider network. Northcott and Hilari (2011) also found that fatigue made people less likely to initiate or arrange social events, and less inclined to want to socialise both in and out of the house. A recent qualitative study exploring fatigue post stroke concluded that fatigue 'was a significant problem in the stroke survivors' struggle to regain a new normalcy.' (Kirkevold, Christensen, Andersen, Johansen, & Harder, 2012)

The blogs also reflected on more positive experiences. These included the value participants derived from groups, including aphasia groups. It has been suggested that there is likely to be benefit from meeting 'experientially similar' others (Thoits, 2011), and other studies have also described the value of meeting others 'in the same boat', helping to normalise the stroke experience (Brown et al., 2013; Ch'ng et al., 2008).

Support received from family, friends and the wider community also emerged as an important theme, including feeling accepted, loved and encouraged. Receiving support was described as facilitating recovery. There is substantial evidence that those who feel well-supported are less likely to become psychologically distressed post stroke (Hilari et al., 2010; Townend et al., 2007), and more likely to make a fuller physical recovery (Glass & Maddox, 1992; Tsouna-Hadjis, Vemmos, Zakopoulos, & Stamatelopoulos, 2000). As such, strong supportive relationships may 'buffer' some of the negative psychological consequences of having a stroke (Cohen & Wills, 1985).

A novel finding in the present project was the emotional value that participants derived from maintaining a blog. It appeared to be a space which was perceived as safe, and where participants could '*learn to just be me*'. Given the disruption to identity that constitutes stroke and aphasia it may be that the self-expression inherent in maintaining a personal blog facilitated the blog authors in doing the 'inside work' (Parr et al., 1997), and may have helped people in adapting to their post stroke life.

There is evidence of the psychological benefits associated with engaging in expressive writing activities such as creating a narrative account of a person's illness experience (Pennebaker, 2000). In terms of the therapeutic value of blogs, a recent study surveyed 230 bloggers with chronic illness in order to explore the psychosocial benefits of blogging (Ressler, Bradshaw, Gualtieri, & Chui, 2012): a main finding was that blogs were perceived as an expressive outlet. Blogs enabled the blogger to make sense of experiences and could act as an emotional release.

Another benefit of blogging to emerge from the Ressler et al. (2012) study was the sense of feeling connected to others: bloggers with chronic illness were reported to feel not 'so alone' with their illness. There is also evidence of health benefits to self-disclosure (Figueiredo, Fries, & Ingram, 2004), and conversely psychological costs to feeling inhibited about discussing one's illness (Herbette & Rime, 2004). For participants in the present project, the blogs were a forum where they could communicate their experiences to family, friends and the wider cyber community in a way that avoided having to manage background noise, follow group conversations, and other reported barriers to successful communication. While it could be an effortful enterprise for some of the authors it was also a form of communication in which the author was under no external time pressure to organise their words, as is the case in most face to face conversations. It is of interest that participants in the present project felt able to write openly about their experiences in their blogs, even though a subset also described avoiding face to face social contact, replicating other stroke studies that similarly found a tendency for people to 'close in' and withdraw into themselves (Dowswell et al., 2000; Northcott & Hilari, 2011). It has been argued that the internet is perceived as a place where non-judgemental exchanges can take place, and in which people can voice their problems without feeling stigmatised (Rier, 2007). Thus blogging may represent a relatively safe and controlled way for those with aphasia to self-disclose and tell their stories.

A strength of this study was the use of blogs which provided a novel data source. Blogs appeared to be a forum where participants spontaneously disclosed intimate details and raised issues that mattered to them. The data is rich in the small everyday details that make up a person's life, and which may be difficult to recall several weeks and months later when probed by a researcher.

Nonetheless, several methodological issues are raised. One limitation of blogs is that it is not possible to verify the identity of the blog author (Rier, 2007). Further, there is no way of

confirming that the narratives represent authors' experiences truthfully. Although some reassurance about people's online identity was provided by the on-going nature of the blogs and by the themes which emerged from the data gathered, nonetheless future research could combine Internet data with other sources of information to strengthen the validity of the emergent themes (Adair et al., 2006).

A further limitation of the passive analysis employed in this study is that no probing or further exploration of issues was possible (Adair et al., 2006), nor was it possible to explore with participants contradictions within an account, or the emotional impact of described events. Moreover, online written accounts do not contain the nuances of spoken language, and visual and gestural cues are missed (Fleitas, 1998).

In terms of the generalizability of the findings, the participants were relatively young, with only two participants aged over 56 years old. Indeed, all but one of the blog authors were in employment prior to the stroke. Further, they were computer literate and able to express themselves in the written form. Thus those with more severe aphasia and older stroke survivors are not represented in this sample. Blog authors with chronic illnesses typically are highly educated (Ressler et al., 2012). It is therefore not clear the extent to which the experiences of those who maintain blogs can be generalised to the wider aphasic population.

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

If the ultimate aim of rehabilitation is quality of life (Department of Health, 2007), then attention needs to be paid to the considerable social costs of having a stroke. Relationships with family, friends and the wider network were crucial elements in the everyday lives of participants in the present project, providing valued support, facilitating adjustment to post stroke life, as well as providing a sense of integration and enjoyable interactions. Yet all elements of the network appeared to be under strain post stroke. This would suggest that clinicians should consider facilitating the maintenance of important relationships as a legitimate therapeutic goal. Indeed, Worrall et al. (2011) found that the goals people with aphasia set for themselves often highlight the importance of family relationships.

Given the particular strains observed within the family unit, another approach may be to offer more support to the family as a whole. It has been argued that significant others of people with aphasia have their own goals and need to be more actively involved in aphasia



rehabilitation (Howe, Davidson, Worrall, Hersh, Ferguson, Sheratt, & Gilbert, 2012), and the National Stroke Strategy states that the health and well-being of the carer is an aim of service delivery in its own right (Department of Health, 2007, p. 44). A recent meta-analysis found that couple-oriented interventions in chronic illness, typically involving education and support, can have significant positive effects, both on patient mood, and also marital functioning (Martire, Schulz, Helgeson, Small, & Saghafi, 2010).

Reduced participation in social activities, in part due to environmental barriers, was another concern raised in the blogs. Making work, education and leisure pursuits more accessible may increase participation (Department of Health, 2007). Yet in order to achieve 'psychological access' (Cruice & Bunning, 2004), public attitudes to aphasia may need to shift. Elman, Ogar, and Elman (2000) suggests limited public awareness results in less empathy and understanding for re-integrating into the community. One strategy for raising awareness could be the writing of blogs, thereby increasing the social media presence of aphasia.

Given the value of groups identified in the blogs, therapy offered in a group context may help to bolster a person's social identity. For example, Vickers (2010) found that those who attended groups perceived themselves to be significantly less isolated and more connected, and participated in more social activities.

In terms of future research, an analysis of the 'comment' sections of blogs, which allow other people to share their experience with the blogger, may provide information about how support networks are created on-line, and what influence they have on the person who maintains the blog as well as the readers of the blog. More generally, further research may usefully examine the role and formation of online support communities for people with aphasia. Finally, this study has shown that writing blogs not only enables a person to feel connected to a wider community, they also appear to act as an emotional release. Future research could further explore with aphasic bloggers the value of maintaining a blog, their motivation for blogging, and the therapeutic potential in this type of outlet.

## **Conclusion**

This qualitative study explores the impact of stroke and aphasia on social relationships. The key strength of the study is the novel data source: the blogs written by those with aphasia.

This provided a highly authentic picture of the concerns and everyday experiences of aphasic life, thus adding new insights to the aphasia literature. People with aphasia described the importance of meaningful relationships and the value of the support they received; they also described the difficulties in maintaining family life and contact with the wider network. A novel finding of the study was the role of the blog as an emotional outlet and a forum for people to share their everyday experiences with family, friends and a wider cyber community. Given the well-described loss of social network and activities post stroke, the sense of connection that can come from writing a blog may have particular value for this population.

**Table One. Participants' background information and demographic characteristics**

Pseudonym	Gender	Nationality	Age	Stroke Type	Year of stroke	Onset of blogging	Stroke-related disabilities	Co-morbid conditions	Living	Children	Employment status		Reasons for not returning to work
											Before	Now	
Jess	F	English	31	LH CVA	2006	2012	Aphasia; Fatigue; STM		Alone	-	✓	✓	
Tom	M	American	67	RH Haemorrhage	2009	2010	Aphasia; Fatigue; Impaired balance; Impaired mobility (unable to walk unaided); seizures; STM deficit	Atrial fibrillation Parkinson's Disease	Wife	2	✓	✗	Aphasia, Fatigue, Age
Nick	M	American	---	LH CVA	2010	2011	Aphasia; Fatigue; Impaired co-ordination; Impaired memory; RS hemiplegia		Wife	2	✓	✗	Aphasia
Emily	F	Turkish	42	LH CVA	2006	2007	Aphasia; Apraxia; Dysarthria; Impaired mobility; RS paralysis; Seizures; Visual impairment		Family	1	✓	✗	
Adam	M	English	56	MCVA (RH+LH)	Late '90s	2008	Aphasia; Dysphagia; Fatigue; Impaired coordination; RS weakness	Diabetes	Family	3	✓	✗	Stroke
Pam	F	American	29	LH CVA	2010	2010	Aphasia; RS facial weakness; Visual impairment		Alone	-	✓	✗	Stroke
Beth	F	American	42	MCVAs	2010	2011	Aphasia; Fatigue; RS weakness; STM deficit	Hypertension Anaemia	Family	2	✓	✓	
Laura	F	American	48	LH CVA	2010	2010	Aphasia; Seizures	Ductal carcinoma in situ	Family	2	✗	✗	
Carl	M	American	69	MCVAs	2002	2011	Aphasia; Fatigue; Impaired sensation; RS paralysis; Visual impairment	Bipolar disorder	Wife	2	✓	✗	Stroke
Rose	F	American	55	LH CVA	2008	2010	Aphasia; Apraxia; Fatigue; Impaired memory; RS paralysis; Seizures		Alone	-	✓	✗	Stroke

Note: CVA=Cerebrovascular Accident, LH=Left Hemisphere, LS= Left Side, MCVAs=Multiple Cerebrovascular accidents, RH=Right Hemisphere, RS=Right Side, STM=Short-term memory

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