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Aphasia blog talk: How does stroke and aphasia affect the carer and their relationship with the person with aphasia?

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Abstract

Background: Carers of stroke survivors with aphasia are at risk of experiencing negative biopsychosocial consequences and reduced quality of life. So far in aphasia studies this has mainly been explored through qualitative interviews and questionnaires. Unsolicited first person narratives in the form of blogs offer a novel and rich source of data to examine how stroke and aphasia affect the carer and their relationship with the person with aphasia.

Aims: This study explored how carers of people with aphasia perceive their roles and responsibilities; it also examined the consequences of carrying out these carer roles and duties, in terms both of the carer's own wellbeing and their relationship with the person with aphasia; further, it investigated facilitative factors in their adaptation to the carer role.

Methods and procedures: Publically available blogs written by carers of aphasic stroke survivors, which included information on how stroke and aphasia affect the carer and their relationship with the person with aphasia, were analysed using the Framework Method.

Outcomes and Results: The search resulted in nine carer blogs. Number of posts per blog ranged 13-241. For blogs containing over 90 posts, the first and last 30 relevant posts were collected and analysed. New roles and extra responsibilities identified by participants included: having to act as therapists, nurses, counsellors, administrators, and carrying out tasks usually assigned to the other person in the relationship. The extra tasks and duties impacted on the carers' quality of life and their relationship with the person with aphasia in negative ways, such as leading to physical and mental exhaustion, health issues, feeling lonely and resentful of their circumstances; however, participants also identified positive changes such as new closeness, new appreciation of life, and pride in achievements. A variety of strategies emerged from the data that helped carers adjust to their new roles. Strategies included positive re-framing, allocating time to oneself, and seeking support from

family and friends. The activity of blogging was also mentioned as having beneficial effects on the carers' well-being.

Conclusions: The study provides further evidence for the specific challenges faced by carers of people with stroke and aphasia; it thus confirms the importance of addressing carer related needs in intervention and considering psychosocial well-being for both the carer and the person with aphasia.

Keywords: blogs, carers, stroke, aphasia, relationships, psychosocial outcomes

INTRODUCTION

Taking on the role of carer for someone who has had a stroke can significantly impact upon the carer's quality of life (McGurk & Kneebone, 2013). The term 'carer' as defined by the Department of Health (2008), is someone who 'spends a significant proportion of their life providing unpaid support to family or potentially friends'. Carers enable many stroke survivors to remain living at home, and are therefore of significant economic benefit to health and social services (Carers UK 2007; Low, Payne, & Roderick, 1999; McGurk et al., 2013). Research has shown that carers of people with stroke experience higher levels of perceived strain and psychological morbidity compared to the general population (Anderson, Linto, & Stewart-Wynne, 1995; Low et al., 1999). The perceived burden of care, psychological strain, and lack of support, compromise carers' quality of life (Cumming, Cadilhac, Rubin, Crafti, & Pearce, 2008; McCullagh, Brigstocke, Donaldson, & Kalra, 2005). This in turn can have a negative effect on the person with stroke, with stress in carers slowing down rehabilitation of the person with stroke and increasing the necessity for long-term institutionalisation (Greenwood, MacKenzie, Cloud, & Wilson, 2008).

Carers of people with aphasia after stroke must learn to cope with a multitude of new roles and responsibilities in order to respond to the needs of the person with aphasia (Christensen & Anderson, 1989; Herrmann, Britz, Bartels, & Wallesch, 1995; Michallet, LeDorze, & Tetreault, 2003; Servaes, Draper, Conroy, & Bowring, 1999). Like other carers, they have to take on more household chores, make legal decisions, deal with finances, oversee medical and personal care as well as being supportive in therapy (Grawburg, Howe, & Worrall, 2013).

Additionally, they have to cope with new responsibilities specifically related to communication, such as translating what the person with aphasia is saying, making phone calls and making decisions on their behalf (Hemsley, Werninck, & Worrall, 2013; Howe, Davidson, Worrall, Hersh, Ferguson, Sherratt, & Gilbert, 2012). Carers of people with aphasia rated communication with the person with aphasia as the most difficult and upsetting issue, followed by managing behaviours. Time for family and friends was also a major issue (Bakas, Kroenke, Plue, Perkins, & Williams, 2006).

The effects of carrying out these extra tasks and responsibilities may be classified as 'third party disability' as proposed by the World Health Organization (WHO) (2001). Carers are likely to experience the impact of additional caring duties on all levels of the International Classification of Functioning, Disability and Health (ICF) (WHO, 2001). In terms of the level of impairment, physical exertion and stress of helping someone with a disability can lead to changes in body function, such as decreased appetite, trouble falling asleep or depression (Threats, 2010). Carers' levels of activity and participation can be affected in many different ways; the most directly affected area may be communication with the person with aphasia (Threats, 2010). Lack of conversation or having different ways of communicating can impact on the carers' recreational activities and their social life, for example loss of shared activities due to communication difficulties or having less time and energy for independent activities (Grawburg et al., 2013; Howe et al., 2012). Loss of language function can also cause significant changes to the relationship with the person with aphasia, and changes in wider family dynamics and roles, which negatively impact on carers' mental well-being (Cumming et al., 2008).

The coping mechanisms carers use to adapt to these changes have not yet been investigated in great detail. McGurk, Kneebone, & Pit-ten Cate (2011) found that positive re-framing, or trying to see things in a more positive light and focusing on what has been achieved rather than what has not been achieved, helped carers cope better with stroke and aphasia related stressors. In Howe et al.'s study (2012) carers reported that they needed to ensure they had their own 'space and... time' away from the person with aphasia, to do things such as participate in hobbies. This helped them to cope with the emotional and mental fatigue they experienced as the result of having a relative with aphasia. More generally, Cohen & Wills (1985) found that adequate social support can be a buffer to protect a person from serious psychological difficulties when faced with a major life crisis.

To date aphasia studies have explored the above topics through qualitative interviews (Grawburg et al., 2013; LeDorze & Signori, 2010) or questionnaires (Bakas et al., 2006; McGurk et al., 2011). This study will take a novel approach by investigating the impact of stroke and aphasia on carers, as it emerges from carers' own accounts in their blogs. The internet offers a previously 'untapped source of knowledge' for qualitative research (Keim-Malpass, Baernholdt, Erickson, Ropka, Schroen, & Steeves, 2013). Unsolicited first-person narratives online represent a naturalistic form of enquiry that is authentic and revelatory and not predetermined by specific questions (Robinson, 2001). Blogs offer a breadth and depth of subjective human experience that is frequently difficult to get in more formalised research settings (Acaster & Wild, 2009; Adair, Marcoux, Williams, & Reimer, 2006). Individuals might be more expressive with regard to sensitive issues, as they can use the relative anonymity afforded by the medium to discuss things they would not otherwise discuss in a face to face research setting (Seale, Charteris-Black, McFarlane, & McPherson,

2010). Additionally, in contrast to current measures used to assess people's life status, blogs allow people to comment on the 'here and now' instead of retrieving past information, which makes the issues raised more direct (Seale et al, 2010).

Analysing blogs will add a novel perspective to research concerned with the impact of stroke and aphasia on carers. It may help identify issues previously unexplored, which in turn could inform intervention approaches to enable clinicians and service providers to more effectively support carers of people with aphasia.

This paper addresses the following research questions:

- (1) How do carers perceive their roles and responsibilities following a stroke and aphasia?
- (2) What are the effects / consequences of carrying out these carer roles and responsibilities on the carer and their relationship with the person with aphasia?
- (3) What factors facilitate their adaptation to the carer role?

METHODS

A passive analysis was used to explore the impact of stroke and aphasia on the carer and their relationship with the person with aphasia. Publicly available data was gathered from the Internet and analysed without investigator interaction with participants (Eysenbach & Till, 2001).

Ethics approval was granted by City University London School of Health Sciences Research Ethics Committee. Internet based research raises ethical issues in terms of privacy and

informed consent (Eysenbach & Till, 2001). In this project we ensured that only publicly available blogs were used. Blog-hosting websites have policy guidelines and terms and conditions that users have to agree to before creating their blog. For example, Tumblr notifies users that “by default all sharing through the services is public and [...] you should assume that anything you publish is publicly accessible unless you have explicitly selected otherwise [...]” (<http://www.tumblr.com/policy/en/privacy>). Other blog hosting sites have similar privacy policies stating the public visibility of all posts. Consequently, it is acceptable for qualitative researchers to use and publish online narratives in their research (Robinson, 2001; Seale et al., 2010). Still, blog authors were contacted and offered the opportunity to opt out of the study. Contact was made either via available email addresses or through posting a comment on their blog. Information was provided in an aphasia-friendly information sheet, using simplified language and visual cues, and a link to a short video explaining the study (<http://vimeo.com/59493861>), as participants may have liked to share this information with their partners with aphasia. Additionally, pseudonyms have been used in this report, instead of people’s names, to protect their anonymity.

Participants and data collection

Participants had to be age 18 and older and carers of people with aphasia. Only blogs written in English were considered. Group blogs were excluded, unless they related to one person with aphasia. Blogs had to be publicly available with no log-in or password required. Blogs were located through searching for keywords ‘aphasia’, ‘dysphasia’, ‘stroke and speech’, ‘stroke and language’ and ‘language problems post stroke’ in blog search engines such as Google blogsearch (www.google.com/blogsearch) and Technorati (www.technorati.com). Search features of blog content management systems such as Wordpress (wordpress.com),

Blogster (www.blogster.com) and LiveJournal (www.livejournal.com), were also used. Further, blogs were located by following links provided on blogs already found. No upper limit on numbers was set. Manual selection and validation was performed by the investigators, who checked the blog authors' profile and the first 10 consecutive posts to ensure they were written by a carer of a person with aphasia, and they contained material relating to the effects of stroke and aphasia on the carer and their relationship with the person with aphasia. Blogs not containing the keywords 'aphasia' or 'dysphasia' in the first 10 consecutive posts were excluded. Where blogs were still active, data was collected up to January 2013. For large blogs, with 90 or more posts, the first and last 30 relevant posts were collected and analysed.

Data analysis

Data was analysed using the 'Framework' method (Ritchie & Spencer, 1994). To minimise bias, all the different stages of the analytic process were carried out by the first two authors, and were then discussed with and checked by the last two authors. 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). Through multiple readings, the investigators familiarised themselves with the content of the posts collected to gain an overview of the key ideas and recurrent themes that appeared in the data. The themes identified were used to create a thematic index. The index was applied to the whole data set; each phrase or passage was assigned a label. For triangulation purposes, a third of the data was indexed by the first two authors separately and findings were compared; there was perfect agreement on 92% of the data suggesting high inter-rater reliability. The indexed data was summarized and synthesized into charts, the chart headings

evolving from the index. In each chart, every participant was allocated a row, and separate subtopics were given 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 distilled, which were then further abstracted and assigned to higher level categories. This process was iterative, with researchers frequently returning to the original documents to check that emerging themes were consistent with participants' accounts.

RESULTS

The search resulted in the identification of 15 blogs. Six blogs were excluded due to lack of material relating to carers' relationship with the person with aphasia. Of the remaining nine blogs, two blogs shared the same author, and in one instance three different authors contributed to the same blog ($n = 10$). In the latter case only one author was contacted for consent. In total, four blog authors were contacted via email, four via the comments boxes. Out of the eight participants contacted, five responded to give consent. No one opted out of the study.

Participant characteristics

Participant information was gathered from blog entries and online blog profiles: there was no direct contact with participants to elicit or confirm details. This means that we do not know explicitly the accuracy of the self-report; moreover, the stroke-related disabilities of their partners with aphasia may not accurately reflect the full range of difficulties experienced. The participants comprised nine females and one male. None of the participants specified their age; an approximate age could be inferred from the ages of their

children or the person with aphasia; participants appeared to range in age from their early twenties (children of person with aphasia) to their sixties (parents and spouses). Nine blog authors were based in the US, one in the UK. All were white Caucasian. Six participants were spouses of people with aphasia; one was the mother of the person with aphasia; and three were daughters (co-authors of one blog). Characteristics of the participants are summarized in table 1.

[table 1 about here]

How do carers perceive their roles and responsibilities following a stroke and aphasia?

Having to take on new roles and extra responsibilities when caring for someone after a stroke was mentioned by all participants. The additional tasks and duties carers had to adopt were wide-ranging, from having to act as therapists, nurses, counsellors or administrators to carrying out tasks usually assigned to the other person in the relationship. One participant summarized this as: *"I've been playing the part of housekeeper, nursemaid, errand girl, psychologist, SLT, PT and wife"* (Angie, C's wife).

Acting as 'therapist'. Taking on therapeutic tasks, alongside or in the absence of trained therapists, featured in most carers' accounts. As the majority of participants cared for people who were severely affected by their stroke, rehabilitation was demanding and involved practising and carrying out exercises in different disciplines such as physiotherapy, occupational therapy and speech therapy. Occasionally, therapeutic tasks were carried out playfully: *"If the cat walks through the room, I snatch him up and say 'what is this?' "*

(Deenie, B's wife). More often, carers commented on the onerous nature of having to manage this. For example, Phil, J's husband, wrote *"I work her out 1-2 times per day in addition to her regular scheduled therapy sessions, don't know how I'm gonna keep this up"*. Being actively involved in rehabilitation also entailed having to become familiar with new equipment, such as electrical muscle stimulation devices or high tech communication aids, as well as motivating the person with aphasia, keeping track of their progress and making sure skills were practised in different settings and not just in therapy. Meagan wrote: *"Went to a restaurant with friends...as usual had D practice what he wanted to order before waitress came back"*.

A problem mentioned by the majority of participants was lack of access to longer term therapy; the reason for this was either lack of service provision or health insurance constraints. This often resulted in the carer having to take responsibility for enabling the person with aphasia to continue with rehabilitation.

Carrying out nursing tasks. Part of most participants' daily routine was performing personal care and nursing tasks for the person with aphasia, such as washing and dressing, cleaning up, managing medication, monitoring appetite and weight, and managing medical crises. Carers whose relatives were more severely affected by their stroke described how physically demanding it was to provide appropriate care. An example is Deenie, B's wife, who described her daily routine as *"Up early, give him his meds, bolus feeding, washing, dressing, change sheets, do laundry, empty urinal, change diapers."* A specific instance that illustrates the stress involved in handling her husband's nursing needs is the following:

"I went to change his bed pad...then I noticed the Peg tube was no longer in B's stomach. This was a first for me. This was a bit of a shock. In fact, it was downright horrifying. And I didn't know what to do. And there was no one to call at 6:30 a.m...[Arranged travel to hospital, B had Peg tube refitted] ...When we got home, I got B into bed, he peed all over the sheets, had to get him out, changed his sheets. I tell you, by the end of the day, I was exhausted."

Although not all participants had to handle this level of nursing care, most carers had to deal with medical situations on a regular basis. One participant, Mary, a young stroke survivor's wife, described the trauma of having to respond to her husband M having an epileptic seizure:

"M had a seizure, called 911, sobbed as I told the operator what was happening. I cried the whole way to the hospital. Watching my husband have a seizure, thinking he was going to die was pretty fucking traumatic."

Providing emotional support. Another part of the caring role was providing ongoing emotional support for the person with aphasia. This included motivating him/her, staying positive, being reassuring, showing empathy and understanding. Encouraging their partner with aphasia to carry out activities or continue with therapy was a common story. Carers often provided a sense of 'being in it together', that helped the person with aphasia persist with difficult situations.

Offering emotional support was not always an easy task. Some carers found they were 'running out of ideas' when thinking of ways to encourage the other person. Jeannette,

whose daughter was overwhelmed by the thought of going back to school, and kept having panic attacks, described how she was trying to make it easier and find positive things to say to calm her nerves but commented: *"I'm not sure I'm being very successful"*.

Administrative and organisational tasks. Administrative tasks such as filling in forms, keeping on top of medical appointments and managing finances featured in most carers' accounts. Many participants commented on the time-consuming nature of being a 'Care Co-ordinator' or 'Medical Manager'. Particularly participants based in the US complained about 'drowning in paperwork'; their health insurance generally required them to fill in lengthy forms and provide medical reports when applying for further rehabilitation.

Having to manage new financial pressures was a prevalent theme, especially amongst female participants caring for their partners, as their partners were often the main breadwinners prior to their stroke. Selling houses, paying for adaptations, buying new equipment, were seen as a demanding and often anxiety provoking part of their roles.

Shifting roles: being 'mummy and daddy'. The lines between traditional roles in the relationship between the carer and the person with aphasia often had to shift. Tasks that typically were carried out by people with aphasia before their stroke, now had to be taken on by those caring for them. Role reversals manifested themselves in a number of different ways. As the majority of participants were wives of stroke survivors, having to take on 'guy things' was mentioned frequently in their accounts. For example, one of the participants, Meagan, expressed sadness about not having a *"go-to guy"* anymore and having to fulfil two roles:

"I get the tires rotated on the Blazer, I get the vehicle serviced, Jeez, I even unplug the toilet and fix its chain when it has PMS...can think of a hundred 'honey-do' things...guy things are creeping up on me, boxing me in the corner...why do I have to be the mommy AND the daddy?"

By contrast Phil, husband and father of three young children, had to take on the role of primary carer of the children, as well as cooking and cleaning, as his wife was unable to take on these roles as she had done prior to her stroke.

What are the consequences of carrying out carer roles and responsibilities?

Carer's own wellbeing: a "rollercoaster of emotions"

There was variation between entries in how individual participants felt about *"being in the caregivers' circus"* (Meagan) and having to manage their new roles and responsibilities. In a lot of cases carers reported feeling exhausted, sad and resentful of the changes; however, with the 'downs' there were also the 'ups', and many individuals cited examples of laughter, progress and pride. This ambivalence of emotions is summarized by Mary:

"Life has been great and weird since M came home from hospital. I'm switching between being angry at M, then euphoric he's alive and suddenly more in love with him than ever, until I remember that his whole life and existence revolves around me taking care of him."

Consequences for the carer's state of mind: "Like a zombie on autopilot". Physical and mental exhaustion were major consequences of fulfilling carer duties. Feeling burned out due to

never-ending chores, lack of sleep, and constant worries were common sentiments amongst participants, as illustrated by Deenie's quote:

At 4.30 am...I drag myself out of bed and find he has spilled his urine bottle again and is soaked...so I clean him up, change his diaper, change the sheets...then crawl back into the bed and lay there in the dark...can't sleep.

Carers commonly described how the person with aphasia's dependence did not allow them time to rest or think. They longed for a few hours on their own, without having to worry about what the person with aphasia was doing, thinking or how they were coping.

Phil, for example, expressed grief over not having an *"adequate amount of free time"* anymore and that having to manage the daily challenges of his caring role had *"robbed him of the possibility of ever attaining a feeling of satisfaction for my own personal accomplishments."*

The lack of time and space to oneself and having to 'take second place' impacted on the way people felt about themselves. Meagan, for example, mentioned that she felt old – *"aged by 10 years"* – and unattractive, as there was no time to look after herself; this made her feel like *"a zombie on autopilot"*, who *"just woke up and lost 5 years fashion savvy"*. She also complained about having lost her sense of self – *"I forgot who I am, what my true swing in life is all about!"* as her life now revolved around caring for D. Phil shared this feeling of having had to change his old 'self' in order to *"adapt to the new situation"*.

Feeling lonely and insular. Participants, especially those looking after their partners, frequently reported feeling lonely and insular, at times *“depressed about the whole situation”* (Lynn). People missed their pre-stroke husband or wife, their physical and emotional support, someone to look out for them, rather than the other way round. They felt alone, and found life harder. They grieved for their partner’s pre-stroke personality – especially having someone to talk to and being listened to, which was often very hard due to their partner’s aphasia, as described by Angie:

“I love my husband, but it is difficult living with an aphasic. [...] I miss someone looking out for me and I miss having long conversations with my husband.”

Mary also wrote about how it *“sucks living with someone with aphasia”*, and how she missed being able to go to M *“for advice, discuss grand plans and have inane arguments”*. She also grieved for times when they could do activities together, such as *“geocaching in inaccessible places”*. It was a recurrent theme amongst participants that there was less time and opportunity to have ‘fun’ together and do things spontaneously. Every activity had to be carefully planned and accommodate the person with aphasia’s stroke related needs: *“went to Dali exhibition as it bills itself as handicap accessible, plus has cafe for cup of thickened coffee”* (Deenie).

Impact on carers’ health. The negative impact of fulfilling carer duties on the participants’ health was voiced, particularly by wives whose partners were fully dependent and whose care was physically demanding. Lynn mentioned how she had been on a *“stress diet since the stroke”*, shocked to see that she *“lost over a stone”*. A very common complaint was back pain from lifting, pushing a wheelchair and manoeuvring someone a lot heavier than

themselves. Deenie, Lynn and Meagan in particular had very similar difficulties, at times requiring help from health professionals themselves, such as physiotherapy to help with lower back pain or knee problems.

Carer's relationship with the person with aphasia

Effects on the relationship. Changes in participants' roles and responsibilities led to changes in their relationship with the person they were caring for. Some people felt this change more keenly than others. If the role pre-stroke involved caring for the person with aphasia, such as a mother-daughter relationship, the change added duties and reinforced the role but did not necessarily lead to shifts in roles as experienced by other carers. Jeanette described how in her case her relationship with her teenage daughter reverted back to a stage when her daughter was much younger and needed more looking after: *"We've discussed our new roles - hers as child and mine as parent...I felt like she was an infant again and I was a new mom"*.

Becky and her sisters on the other hand, whose father was affected by a stroke, took on a new role, as they were now carrying out parenting type tasks such as assisting him with activities of daily living, supervising him during activities, encouraging him to practice his exercises: *"We play games daily, number games come easy, cards, Yahtzee. Dad loves sunshine...we take him for strolls in the courtyard"*. (Becky)

In this project, spouses caring for their partners appeared to be hit hardest by the new circumstances. For example, Meagan, called the change a *"step backward in the area of human relationships"*:

"It felt like I'd had to trade in another, more beloved label to get the caregiver status...went from best friend to caregiver with D. I remember the first time someone called me a 'caregiver': 'Are you your dad's caregiver?' ...it really hurt...it was the first time I realized our relationship had truly changed with the stroke, being mistaken for daughter and father."

Not wanting to be the 'rational partner' in the relationship or having to be the primary decision maker was a commonly expressed feeling by participants. Phil described how making "tough decisions" was an "unfortunate part of life as a caregiver" and that thoughts like "what if I choose wrong" can "haunt you and make it much more difficult to sleep at night".

Resentment of relentless tasks and duties: "pushing rocks with feathers". Most participants expressed sadness and a degree of resentment towards their partners' impairments. Aphasia appeared to be the most difficult and frustrating impairment to live with, as illustrated in Lynn's example: *"I keep wishing there was an injection for this rather than his arm...is that wrong? I would rather he talked to me, seems more important than arm movement."*

Having to compensate for difficulties, especially having to facilitate conversation was seen by many carers as an exhausting task; communication breakdown could lead to negative feelings and tensions with the person with aphasia.

“Today has been a real pushing rocks with feathers day due to this damn aphasia making its presence well and truly felt. We have had several episodes of P wanting to say something and me just not getting it, despite trying my best.” (Lynn)

A sense of rejection and resentment was also felt by participants, when the person with aphasia was not cooperative with tasks; when the carers tried hard to do their jobs, and their effort was met with bad moods or even tantrums. Especially Deenie, Lynn and Phil felt that their partners were more cooperative with other people than themselves, such as therapists, friends or other family members.

One participant, Phil, was particularly hurt by a lack of gratitude on the part of J his wife: *“the look in your loved one’s eyes as you prepare meds is one of annoyance... the expression as you help them out in the bathroom one of disdain”*. He expressed a reduction in self-worth as he felt he was under-appreciated by J, considering the amount of work he was doing for her and his family. He wrote that the worst part of caring was *“doing so much and being appreciated so little”, “rarely if ever do you hear a ‘thank you’”*.

Positive impact on the relationship. Having a laugh and looking at the humorous side of caring was less common in people’s accounts, however, there were examples. Some participants made jokes about their own nursing skills and most of them did see the humorous side of the impairments of the person with aphasia. This humour was generally shared with the person with aphasia. For example, Mary occasionally felt entertained by her husband’s *“nonsensical aphasic conversations”*; she described an incident where she was amused by being called *“Salad”* rather than *“Mary”*.

The frustrations of not being able to understand what the person with aphasia was trying to communicate were at times balanced out by the joy felt when they were able to get to the bottom of a message, as in this example by Meagan:

My sense of humour was coming back...my aphasia decoder FINALLY broke the damn code 'You want me to turn the valve on full force...!' 'Yes!'...D plastered kisses on my face and hair...such is our life on Planet Aphasia.

Others mentioned moments of feeling proud when mastering new skills and achieving goals, such as becoming an expert communicator, getting health care funding for their partner or learning how to place a catheter.

Furthermore, the extra tasks and extra time spent together often resulted in a new closeness. Carers talked about 'new love' and 'new bonds' as a result of going through the stroke experience together. Taking stock, appreciating what is left and feeling proud for being able to manage the person with aphasia at home - thus avoiding a nursing home - was a common sentiment. An excerpt from Deenie's blog illustrates this:

*Long damn 2 years, without vacation, weekend, holiday off or a decent night's sleep!
Also 2 years without hospitalization or infection, and B has gained back weight and is happier and healthier than ever and loves being home.*

Another source of motivation for working together as a team was the progress that was achieved, through the drive and tenacious attitude of the person with aphasia and the hard

work offered by the carer. This meant that in some cases the initial medical prognosis of 'vegetable for life' was proven wrong.

What is described as facilitating the carers' adaptation to the carer role?

Participants described a variety of ways that helped them cope with the stress involved in caring for people with aphasia after the stroke, for example, drawing on memories, feeling appreciated, receiving support from family and friends. Strategies such as focusing on the positives, on small improvements, allocating time to themselves and using the blog as an outlet to vent their feelings also helped them cope better with their new circumstances.

Positive thinking and viewing life as a 'journey'. Reflections on life and death were common in participants' accounts. Taking events into perspective and feeling grateful for 'what's left', feeling blessed for still having the person with aphasia in their lives, helped them come to terms with new challenges. Deenie, for example, described the horror of the time when she had to authorize her husband's DNR (Do Not Resuscitate) form, which reminded her *"how much worse it could have been and how blessed we are"*. Thinking about death and *"taking a step back now and again"*, seemed to lead to a new appreciation of life, as illustrated by Mary's quote: *"Choosing to take this mini-epiphany as motivation to get off my ass, smell the flowers, hug my mother etc. You should too."*

Looking at the bigger picture, viewing the stroke experience as one part of a longer journey seemed to make the difficulties of the present more bearable and brought the carer and the person with aphasia closer together, as described by Meagan: *"I view these*

caregiver/survivor years as just another chapter in a long book of chapters... we've done a lot of living and growing together."

Some participants mentioned how drawing on past events helped them cope better with the present and also helped them gather strength for the future. Even though memories could make carers feel sad about what they had lost, reminiscing could also be a source of happy thoughts and helped strengthen the relationship they had with the person with aphasia, it helped 'bind them together' through a shared history.

"Thumbing through our book of chapters is not about wishing for the past. It's about loneliness that is often hard to bear. It's about being two peas in a pod, half of a whole. Reminiscing is a reminder of why we caregivers choose to stay when others might run". (Meagan)

Taking comfort in small steps. An attitude that helped people steer through difficult times was to focus on progress; starting to enjoy life again by treasuring the small gains and making a conscious choice of living in the moment. Phil said about J *"seeing her vacuum is quite exciting"*. According to Meagan the *"Caregivers' Cardinal Rule is about appreciating what is here, right now"*. Shifting the thinking to how far they have come rather than what was still missing or worrying about the future helped people carry on. Deenie described such a moment: *"Then he began to walk, a miracle. [...] B is finally able to wear shoes as his pressure sores have cleared up, for some reason, seeing him in shoes just thrills me."*

Getting recognition from the person with aphasia. Being appreciated for their work and the extra effort involved in fulfilling the carer's role meant a lot to participants, as was

mentioned earlier. Participants also valued getting recognition as partners, in the form of compliments, birthday and Valentine's Day messages, or the person with aphasia remembering their wedding anniversary. Mary described how *"spontaneous expressions of love"* from her aphasic husband made her very happy: *"'You're pretty', said M. Love it when he can say exactly what he means to say, nice when turns out to be compliments."*

Support received from family and friends. Most participants expressed gratitude and appreciation towards support received from family members, friends and other social contacts, e.g. members of their church. The support offered ranged from hands-on help, such as assistance with home adaptations, help with personal care or therapy activities, to emotional support, provided in the form of flowers, cards, blog posts or prayers. Carers described how the 'kindness, generosity and well wishes' of other people made them feel less alone, reduced their stress levels and generally helped them to 'keep going'. For Jeanette it had an even more far reaching effect:

"Can't even express how much this has done to lessen my worries...it's wonderful to know that there are so many caring people in our lives, it is terrific...thank you...you've not only helped lessen our stress regarding B, you've also helped lessen my cynicism towards mankind as a whole...this is no small feat."

Phil mentioned repeatedly how much he appreciated friends and family members actively assisting his wife with workouts and therapy sessions. He felt it relieved tensions between them, as she responded better to other people giving her instructions rather than him constantly telling her what to do. It also meant that he had some time to himself. In a number of his blogs he explicitly thanked his helpers, and reflected on how different things

might have been without them: *“Without your support I may have been forced to put J into a skilled care facility instead of having her move into our home.”*

Allocating time to self: ‘I actually got to leave and go get coffee!’ As mentioned in the previous paragraph, having time to oneself was rated highly amongst participants. If the person with aphasia was in safe hands with, for example therapists, teachers, or with family or friends, the carers were able to enjoy some activities on their own. Going to the gym, gardening, reading a book, having coffee, getting a manicure or meeting up with friends were mentioned, amongst others. Having that time and space appeared to have a significant impact on their quality of life. Lynn looked forward to a regular meet up with friends, while her son helped with ‘daddy-sitting’: *“I feel I am ready for an evening of girls and gossip!”*. Meagan managed to regularly *“sneak away in the wee hours of the morning to do something for myself”*; *“Years of putting D’s stroke related needs first has earned me two sessions a week in the pool where I don’t have to think and do ‘stroke’ 24/7... life is good.”*

Blogging. Blogging also constituted an activity and a time participants had to themselves. It was an outlet for their emotions as well as a place to share their experiences, their ‘ups and downs’, with other people. Reaching out to others, especially family, friends and other carers, helped them feel connected and less lonely. It was their *“support in cyberspace”* (Angie). Lynn, who talked most explicitly about blogging, called it *“her therapy”*. She described its positive effect on her well-being: *“I feel much better after yesterday’s rant - reason for blogging works”*. For most participants, blogging appeared to be an activity they carried out independently, however, one participant, Phil, mentioned sharing the journal

entries with his wife; he described reading them to her before publishing them. It was quality time for them as a couple – *“one of the best things we do each month”* and the thought that many people were reading about J’s progress was *“enormously motivating”*.

DISCUSSION

This study sought to explore how stroke and aphasia affect the carer and their relationship with the person with aphasia as it emerged from carers’ blogs. Carers had to take on multiple new roles which impacted on their quality of life and their relationship with the person with aphasia in negative ways (physical and mental exhaustion, health issues, feeling lonely and resentful of their circumstances). However, participants also identified some positive changes such as new closeness, new appreciation of life, and pride in achievements. Strategies that helped carers adjust to their new roles included positive re-framing, allocating time to oneself, seeking support from family and friends. The activity of blogging was also mentioned as having beneficial effects on the carers’ well-being.

The role changes and new responsibilities mentioned by participants in this study correspond to findings in previous literature. It is well documented that the role of caring often means having to do three jobs - doing what the person with aphasia used to do in addition to the carer’s own responsibilities - as well as looking after someone; this has been thoroughly described in other qualitative studies (Grawburg et al., 2013; Herrmann et al., 1995; Michallet et al., 2003). The high demands of the caring role are often exacerbated by limited support from outside agencies (Denman, 1998). As was highlighted in the

introduction, literature suggests that carers supporting people with aphasia tend to face a wider variety of additional tasks than carers looking after stroke survivors without aphasia (Bakas et al., 2006; Christensen & Anderson 1989; LeDorze & Signori, 2010; Michallet et al., 2003; Servaes et al., 1999). In our study, the sometimes severe language disorders experienced by people with aphasia exacerbated the burden of tasks such as organizing therapy or medical care, dealing with finances, actively supporting the social interactions of the person with aphasia or making decisions on their behalf. The inability of the person with aphasia to communicate well had a considerable impact on the interpersonal relationship between them and the carer; this makes necessary role adjustments more difficult, as has been reported in studies by Christensen & Anderson (1989) and Herrmann et al (1995).

On the whole, participants in the present study wrote extensively about the effects the extra caring tasks and duties had on them and their relationship with the person with aphasia. This demonstrated that blogs, which are individualistic and intimate forms of self-expression, form a particularly useful source of information on these aspects of the carer's experience. Many of the consequences reported by the participants in this project (e.g. physical and mental exhaustion, low mood, caring related health problems, lack of time to self, having to 'take second place', changes to sense of identity) are similar to findings in previous research (Michallet, LeDorze, & Tetreault, 2001; Servaes et al., 1999, Threats, 2010).

The majority of participants described feeling lonely and isolated, missing their pre-stroke partner, which to a great extent appeared to be due to the severe communication difficulties and the person with aphasia having lost their primary means of self-expression. A meta-review by Servaes et al (1999) found that communication with the person with aphasia was

rated as most upsetting and difficult by carers, with the difficulties ranging from not being able to understand the person with aphasia to missing someone to talk to and share experiences with.

Although participants provided a lot of information on how the impairments and new tasks were burdensome and often led to resentments and tensions in their relationship with the person with aphasia, some of them also acknowledged positive aspects of the caring role. Having a laugh together, mastering new skills, feeling proud of progress and experiencing a new closeness in the relationship were mentioned in people's accounts. This is in line with findings of a study by Grawburg et al. (2013), which is the only other study that investigated the positive effects of stroke and aphasia on carers.

Another observation from the dataset is that although blog authors were generally very revealing about how they felt about themselves and the person with aphasia, the blogs were less rich in information on how the carers felt about their family and friends. Most comments on family and friends were of a positive nature, for example, thanking them for their support, whereas findings in other studies showed that carers often complained about a significant loss of their social contacts and experiencing negative changes within family dynamics (Barkas et al., 2006; Grawburg et al., 2013; McGurk & Kneebone, 2013; Michallet et al., 2001; Servaes et al., 1999). The scarcity of information in this area is likely due to the public nature of the blogs, as well as the fact that part of the motivation for writing a blog was often to keep family and friends updated on the person with aphasia's condition and their progress. In contrast, carers did not seem to feel the same restraint when talking about

the people with aphasia, as in the majority of cases the severe language difficulties restricted them from accessing the blog.

Another aspect that was not discussed in terms of relationship changes by any of the spouses of people with aphasia in this study was decreased sexual satisfaction since the stroke. A number of other studies have reported this to be a common phenomenon (Michallet et al., 2003; Servaes et al., 1999; Threats, 2010); again, it is probably not a topic people would want to discuss in an open forum.

Participants in the current project developed a variety of psychological approaches to help them in coming to terms with their new roles, ranging from changing their attitude towards their circumstances, actively taking control of their situation, or finding ways to release their emotions. Thus it may be that positive re-framing can help a person to adjust to difficult situations (McGurk, 2010). Participants that focused on improvements and showed appreciation of the current abilities and personality traits of the people with aphasia appeared better able to perceive stressors less negatively. Allocating time to themselves to participate in hobbies or meet with friends were also important adaptive strategies (Denman, 1998, Michallet et al., 2003, Howe et al., 2012). Social support has stress buffering effects and is associated with increased well-being, which can influence a person's ability to handle serious life changing events (Cohen & Wills, 1985; Visser-Meily, Post, Van de Port, Maas, Forstberg-Waerleby, & Lindemann, 2009).

The current project is particularly interesting in terms of the activity of blogging as a coping strategy. The benefits of expressive writing and constructing first person narratives are well

known. The act of constructing stories is a natural human process that helps people organize their experiences into something meaningful and structured (Keim-Malpass et al., 2013). Confronting anxieties and problems by creating a story to explain and understand past and current life concerns improves physical and mental health in a variety of populations (Pennebaker & Seagal, 1999). Blogging, though, is more than expressive writing; it is a social process (Pennebaker & Chung, 2011). Studies have shown that self-disclosure through blogging can increase perceived social support (Baker & Moore, 2008) and subjective wellbeing (Ko & Kuo, 2009).

A limitation of this qualitative study is that the findings cannot be generalized to the stroke carer population as a whole. Sampling might reflect inequality in access to the Internet (Seale et al., 2010). The majority of participants are white American females, which is consistent with data that suggests that the majority of bloggers today are from the United States and that female bloggers are more likely to blog on personal topics (Guadagno, Okdie, & Eno, 2008). Carers who post experiences might be different in characteristics such as motivation and ability to express themselves from others in a similar position (Robinson, 2001). Full demographic and medical information is lacking; in many cases this information had to be inferred from the data. As with all Internet data, there is no guarantee that stories posted actually represent the blog author's experience truthfully (Acaster & Wild, 2009). Audiovisual cues are missing and probing or follow-up questions cannot be asked (Adair et al., 2006). Also, the amount of data extracted from each blog varied as some blogs were richer in data than others.

A key strength of the study is its use of online data as a new and innovative way of capturing the naturalistic experience of someone caring for a person with stroke and aphasia, thus adding a new perspective to previous research in this field. A wealth of online material was accessible to the researchers. The methodology used was driven by the original accounts of the participants. The data elicited was immediate and unsolicited, which enabled valuable insight into the day-to-day concerns of the blog authors (Acaster & Wild, 2009). Even though the findings cannot be broadly generalized, they can still be considered useful in understanding the needs of similar populations (Ritchie & Lewis, 2003).

Clinical implications and future research

The current study provides valuable insight into the perceptions and experiences of carers of people with aphasia. In participants' accounts there was little evidence of specific support received for their own needs as carers. This is likely due to a lack in services for this particular client group. Following on from Howe et al.'s (2012) study, this project confirms the importance of addressing carer related needs in the rehabilitation of people with aphasia. By including family members in the rehabilitation process and helping them identify their own goals, clinicians can enhance effectiveness of rehabilitation and psychosocial well-being for both the person with aphasia and their carer. This may include approaches such as the provision of adequate information, specific training, respite care, support groups (Denman, 1998) and counselling based interventions (McGurk, 2010). Developing a policy or guidelines concerning carer support, and providing adequate funding for its implementation would constitute an important step towards minimising the negative long-term effects of stroke and aphasia on the carers' quality of life.

In terms of future research, as the majority of carers in this study were spouses of people with aphasia, further investigation could focus more specifically on how parents, children or friends of people with aphasia perceive caring roles. Another future direction could be to further explore the type of carer that blogs and to find out to what extent it facilitates their resilience to change. Finally, more research is required to explore the likely long-term cost savings that could be realised if carer support were to be put in place, potentially avoiding the 'double bill' of caring for the people with aphasia and treating the physical and psychological illness of the carer.

CONCLUSION

This study explored systematically how stroke and aphasia affect the carer and their relationship with the person with aphasia as it emerged from carers' blogs; this medium provided a rich source of naturalistic data. Participants in the study were affected by a number of role changes and new responsibilities, many of which were exacerbated by the loss of language function that characterises aphasia. The extra tasks and duties impacted on the carers' physical and mental health and led to feelings of loneliness and resentment. Nonetheless, on occasion participants also identified positive changes. Strategies like positive re-framing, having time for oneself, including blogging and seeking support from family and friends helped carers adjust to their new roles. The overall results of the study provide further evidence for the specific challenges faced by carers of people with stroke and aphasia and confirm the importance of supporting them as well as the people with aphasia in the rehabilitation and adaptation process.

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Table 1. Participant characteristics (n = 10)

| Pseudonym | Relationship to person with aphasia | Gender | Age | Ethnic group | Marital status | Children | Person with aphasia – stroke / aphasia description in blog | Carer's occupation | Blog duration and size |
|--------------------------|--|---------------|---------------|----------------------|------------------------|-----------------|--|---------------------------|-------------------------------|
| Angie | Wife | Female | Not specified | White American (USA) | Married | No children | C, male, age not specified Stroke in 2011 Severe aphasia Right hemiparesis Uses attendant propelled wheelchair | Not specified | 2011 - 2012; 91 posts; |
| Becky, Cathy Anna | Daughters | Female | Not specified | White American (USA) | 1 married, 2 unmarried | No children | G, male, age not specified Stroke in 2010 Severe aphasia Right hemiparesis Able to mobilize with supervision | Not specified | 2010 – ongoing; 59 posts*; |
| Deenie | Wife | Female | Not specified | White American | Married | No children | B, male, age not specified Stroke in 2010 | Writer | 2011 – ongoing; 241 posts*; |

| | | | | | | | | | |
|-----------------|--------|--------|---------------|----------------------|---------|--------------------|--|----------------|----------------------------|
| | | | | (USA) | | | Severe aphasia and dysarthria Right hemiplegia Uses attendant propelled wheelchair Incontinent | | |
| Jeanette | Mother | Female | Not specified | White American (USA) | Married | 2 teenage children | B, 16 year old female Stroke in 2010 Mild aphasia Right hemiparesis Independently mobile | DJ | 2010-2011; 66 blogs; |
| Lynn | Wife | Female | Not specified | White British | Married | 2 grown up sons | P, 61 year old male (at start of blog) Stroke in 2012 Severe aphasia Right hemiparesis Able to mobilise with stick | Domestic staff | 2012 – ongoing; 99 posts*; |
| Mary | Wife | Female | Not specified | White American | Married | 1 young child | M, male, 32 Emergency services worker | Not specified | 2012 – 2013; 46 posts; |

| | | | | | | | | | |
|---------------|---------|--------|---------------|----------------------|---------|------------------|---|---------------|--|
| | | | | (USA) | | | Stroke in 2011 Severe aphasia Right hemiparesis and spasticity Able to mobilize short distances | | |
| Meagan | Wife | Female | Not specified | White American (USA) | Married | No children | D, 64/65 year old male (at start of blog) Stroke in 2000 Severe aphasia/apraxia Hemiplegia Uses electric wheelchair | Not specified | Blog 1: 2007 – 2012; 94 posts; Blog 2: 2007 - 2012; 13 posts; |
| Phil | Husband | Male | Not specified | White American (USA) | Married | 3 young children | J, female, age not specified Amniotic embolism Severe aphasia Right hemiparesis Able to mobilize with stick | Not specified | 2010 – ongoing; 47 posts*; |

*number of posts up January 2013