

# **“The experience and expression of social cognition changes for stroke survivors”**

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Doctorate in Applied Psychology

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## **Declaration**

I confirm that the literature review, research report and service evaluation  
contained within this thesis have not been submitted  
for any other degree or to any other institution

## **Acknowledgements**

For ‘all my relations’.

## Word Count

Section	Abstract	Text	References
Part 1: Critical Literature Review	242 words	5923 words	850 words
Part 2: Research report	103 words	11,114 words	1768 words
Part 3: Reflective Critique		3981 words	
Part 4: Service evaluation	295 words	5899 words	846 words
Total text word count		26,917 words	

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# Thesis summary

## **The experience and expression of social cognition changes for stroke survivors”**

### **Thesis Abstract**

This thesis is comprised of four parts: A literature review, a research paper, a reflective critique of the research process and a service evaluation.

**A systematic literature review** was undertaken concerning longer term stroke survivors accounts of social and emotional challenges after stroke. This resulted in 12 studies which were then explored. All 12 studies used qualitative approaches and sought to gain direct accounts from stroke survivors concerning these issues. The studies collated accounts from stroke survivors about their social and emotional experiences through particular study lenses of social support, social participation, quality of life, quality of friendship, quality of spousal relationship and personal perspectives. The studies were then examined in order to understand their contribution to the literature. Across the studies it was clear that from the stroke survivors viewpoint, rehabilitation service models tended to be focussed on early intervention and lacked a longer term strategy which supported emotional and social adjustment. Five main themes across the studies were identified. These were: Loss & Maintenance of friendships; Losses in Social world and role leading to isolation; Social participation & community integration changes; Pre and post stroke self, continuous/discontinuous self; and Emotional responses. These themes were examined more closely in order to appreciate their thematic meaning for stroke survivors and the contribution the various studies had made to this. Recommendations for future research from these results are discussed.

**A research study** interviewed six stroke survivors (ranging from 1-9 years post stroke) in order to gain their views and experiences about any social cognition changes since their stroke. Open ended qualitative interviews were recorded verbatim and then analysed using Interpretative Phenomenological Analysis. Three superordinate themes emerged from this analysis: My changed sense of self in relation to others; Managing my social behaviour; and My altered states of feeling. Each of these superordinate themes contained a number of sub themes. Stroke survivors’ self-understanding of these issues and their views about the impact this has had on relationships is discussed and recommendations are made.

**A reflective critique** records the personal experiences of the author during the research and thesis process. This describes the challenges and lessons of engaging in the academic and research process for this thesis.

**A service evaluation** describes the establishment and provision of a six month pilot offering an in house psychological service for staff within an acute medical hospital alongside a physiotherapy service. Psychological services were offered as a brief treatment model and also provided consultancy and training to staff at all levels. Over the six months, 53 members of staff were seen for direct psychological consultation/treatment. Data were collected regarding professional group, and frequency of sessions and the

effectiveness of the service on staff well-being was measured using the HADS as a measure of individual change. Organisational sickness absence data was gathered as a measure of the pilots cost effectiveness within the organisation. Data were also collected on the types of issues that staff presented with and the category of staff that attended. Results showed that staff anxiety decreased at a highly significant level, and depression at a significant level, but the level of returns of the questionnaires was very low. Staff sickness absence due to stress was compared to the same six months of the previous year and had decreased by 40% resulting in substantial cost savings. Staff sickness across the division dropped from 5.29% to 3.87% over the 6 months. Staff reported sleep problems, low mood and emotional events as the most frequent issues that made them stressed, but loss of confidence in work role and being affected by events at work were also frequently reported; indicating the importance of a service that links in to the organisation. The treating psychologists reported bereavement issues as the most common treatment issue arising from users of the pilot. The evaluation is critically discussed, comparisons are made to published information about the national picture and recommendations are made for future evaluation and research.

## **Part 1**

# **CRITICAL LITERATURE REVIEW**

**Longer term Stroke survivors accounts of social and emotional challenges after stroke – a review.**

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## **Abstract**

Stroke directly affects 152,000 people in the UK alone and for the survivors is the largest cause of longer term and complex disability. Quality of life is affected for stroke survivors due to physical, communication and cognitive disabilities from the stroke which in turn affects emotional responses, social abilities and relationships. This review evaluated those studies that have sought to gain direct accounts from stroke survivors concerning these issues. From an extensive literature search, twelve qualitative studies were identified whose methodology involved collating accounts from stroke survivors about their social and emotional experiences through particular study lenses of social support, social participation, quality of life, quality of friendship, quality of spousal relationship and personal perspectives. These twelve studies were then examined in order to understand their contribution to the literature. Across the studies it was clear that from the stroke survivors viewpoint rehabilitation service models tended to be focussed on early intervention and lacked a longer term strategy which supported emotional and social adjustment. Five main themes from the study were identified: 1. Loss & Maintenance of friendships. 2. Losses in Social world and role leading to isolation. 3. Social participation & community integration changes. 4. Pre and post stroke self, continuous/discontinuous self. 5. Emotional responses.

These themes were examined more closely in order to appreciate their thematic meaning for stroke survivors and the contribution the various studies had made to this. Recommendations for future research from these results are discussed.

## **Introduction**

Every year an estimated 152,000 people in the UK have a stroke and of those that survive is the largest cause of complex disability. As a result, more than half of all survivors are left dependent on others for everyday activities (UK national statistics on stroke December 2012). Eighty five percent of strokes occur when an artery in the brain is blocked (ischaemic stroke) and 15% are caused by bleeding within the brain (haemorrhagic stroke).

Stroke incidence increases with age, but around a quarter of all strokes occur under the age of 65, and around 400 children (0-18) have a stroke each year. Stroke is the most frequent cause of complex disability in adults.

More obvious effects from stroke include physical disability to the limbs, altered sensation spasticity and pain; but there are far more less visible effects including swallowing issues, dysarthria and aphasia, visual problems, poor bladder control and incontinence, emotionalism, altered mood states and depression. Any and all of these post stroke effects take their toll on the \*stroke survivor (SS) emotionally and socially. The proportion of acute stroke patients presenting with one or more mild to severe communication-related impairments has been reported to be as high as 88% (O'Halloran, 2009). A range of aphasic difficulties can persist estimated at 21% to 38% (Pedersen, 1995; Engelter, 2006) following stroke. Those with predominantly right hemisphere injury have been shown to have different difficulties with communication. Patients with right hemisphere communication disorders show changes in the way they use language, pick up on unstated or additional information (for example, making inferences or the use of facial expression) and fail to apply previously learned rules of conversation (Borthwick, 2012).

*\*Stroke survivor abbreviated to SS throughout the text*

Post-stroke fatigue occurs in around 50% of SSs and is frequent (30%) even after minor strokes (Annoni, 2008). It can last more than one year after the event, and has a different quality from usual fatigue where rest is helpful. Fatigue is associated with profound deterioration of several aspects of everyday life and with higher mortality (Glader, 2002) and is still very much a neglected issue (Aglaiia, 2012).

Douri (2013) from their study of post stroke cognitive impairment using the South London stroke register 1995 – 2010 found that the prevalence of cognitive impairment after stroke remained persistent over time. Patel (2003) also looked at survivors from the stroke register finding that cognitive impairment remained highly prevalent up to three years after first stroke; but that recovery was associated with life style factors and the presence of other physical disabilities.

Post stroke lowering of mood is also well documented (White, 2008); indicating that mood changes can occur well beyond early discharge.

The psychological effects of coping with complex disability, rehabilitation and adjustment have led to specific government publications recommending resources for psychological interventions as an integral part of stroke care. SS feedback regarding very poor levels of psychological support in order to cope with stroke as a long term condition was part of a Care Quality Commission review (2011). This document recommended psychological services as part of a step care model, clearly showing the cost benefit of including a psychologist as part of the multidisciplinary care team; recognising the importance of psychological factors in stroke recovery.

At least 500,000 SSs are dependent on someone else to help them in their everyday lives. Many of these carers are family members, so relationships following stroke survivorship are crucial in long term recovery and in maintaining good mental health for both survivors and carers. A number of studies clearly indicate high levels of stress and anxiety for carers



of SSs (Greenwood, 2010; Lincoln, 1998; Hodgson 1996). Qualitative studies such as the research by Hunt and Smith (2004), describe how for carers, the strength of their relationship with the SS is important even from very early in recovery.

Eslinger (2002) developed a clear classification of social executive processes and social impairments that could occur after stroke. The American Society of Neurorehabilitation worked on a wide ranging consensus in order to conceptualise functional cognition following stroke (Donovan, 2008). Amongst the ten cognitive areas in their taxonomy were: social use of language, emotional function, and executive function, in addition to more straightforward language impairment. These three areas included Eslinger's descriptions of the particular challenges for the SS in being able to (i) understand social rules (ii) understand and use social language appropriately (iii) have awareness of one's own and the emotions of others and (iv) be able to juggle that information when needing to address other kinds of problem solving tasks.

The National Stroke Strategy (2008) clearly states that longer term psychological adaptation to the effects of stroke for both survivors and carers are viewed as one of the main challenges in recovery. Specific mention is made regarding depression in stroke survivors and their relationships. Therapeutic work using a relational biopsychosocial model with families has added substantially to the understanding and promotion of a relational focus within more traditional therapeutic approaches in acquired and traumatic brain injury services (Bowen, 2010).

It is recommended that clinical psychologists and other rehabilitation staff need to have conversations with SSs and their carers about social and emotional issues that can arise following stroke. This is not just about the deficits that occur from a stroke, but also about living and relating socially in a meaningful way given the multitude of challenges.

This review aims to evaluate the research concerning SSs own views of how their stroke impacted upon their social and emotional abilities.

## **Method**

Initial scoping for the review began by looking at the literature produced by the Stroke Association and the younger stroke survivor group ‘Different Strokes.’ With regard to emotional and social ability this literature described personality changes, mood change and carer stress as important issues for SSs. The information was consistent and gave some guidance regarding typical reactions that can occur for the SS and their carers (see self-help leaflets provided by the Stroke Association).

A systematic review of the literature was then conducted using the main electronic databases – EBSCO, PsychINFO; Psych ARTICLES; PsycEXTRA; Ovid Medline, Embase, Google scholar, Scopus Web of science / Web of knowledge.

Identified articles were then screened for their relevance to the subject area by scanning titles and abstracts and using the exclusion and inclusion criteria detailed below. Where the relevance of the article was unclear, the articles were retrieved and read in their entirety to examine how they might be relevant to the literature search question.

## **Search terms**

Databases were initially searched through article title and abstracts using the following search terms; [CVA OR Stroke] AND [social cognition OR emotional processing OR social skills OR empathy OR self-concept OR self-awareness OR personal experience OR emotional intelligence OR social intelligence OR social relationships OR coping behaviour]. A total of 712 studies were found relating to these terms not excluding duplicates between databases. All the abstracts were read and considered based on the following inclusion and exclusion criteria.

## **Inclusion criteria**

Articles that were included were

1. Peer reviewed
2. Applied to adults over 18 years
3. Those published between 1996 and 2013. This was because ‘emotional intelligence’ was first coined in 1996 (Goleman, 1996) building on already established ideas about interpersonal ‘social intelligence’ (Ruisel, 1992); allowing for more psychological enquiry into the inter and intrapersonal experience.
4. Those that stated that social and emotional effects for SSs were an important part of their study.
5. Studies that were looking at longer term effects for SSs. ‘Longer term’ was judged by the author to occur after the initial physical and psychological adjustments had been made and a longer term criteria of ‘minimum of 1 year’ allowed for that to occur.
6. Studies that included description of themes or patterns of responses from the SSs themselves.

## **Exclusion criteria**

Articles were excluded systematically when they did not investigate the experience of stroke from the SSs point of view (appendix A). The search stopped when all the relevant data bases had been searched, no new studies were becoming available and the same studies continued to arise.

The 12 selected articles for review were all qualitative studies and the author believes them to have been representative of current research in this subject area. A closer examination of the selected papers was carried out and details were extracted into a Key Papers Table (appendix B). The table describes the recruitment method, inclusion and exclusion criteria,

geographical location, participants, and the time elapsed since the stroke. It shows how the studies described their method and design, their focus or philosophical position and any other observational or data gathering techniques. The table comments on the analysis and outlines the limitations. Key themes and results are noted for each of the studies. Of the 12 studies included as appropriate to this review, all of them were pertinent as they had used a research framework to explore SSs' views of their recovery and within this there was some description of emotional and social relationships.

## **Results**

The 12 papers were initially scrutinised to present general similarities and comparisons in order to present an overview. This overview discusses geographical location and focus of the different studies, their analytic methods and the general characteristics of participants. Following this a review was conducted of the themes that emerged from the studies and their contribution to accounts of social and emotional challenges following stroke.

### **1. Geographical Location and study focus**

Of the twelve studies: five were based in the USA, three in the UK, two in Australia, one in Ireland and one was across UK, Canada and USA. The foci of the studies included: quality of life and social participation/social function (n=3); personal accounts of experiences following stroke (n=3); friendships following stroke (n=2); the role of social support after stroke (n=1); two case studies using personal accounts and other information (n=1); invisible disability in younger SSs (n=1), SSs' views of their spousal relationships (n=1).

### **2. Types of qualitative methods used.**

The research methodology used by those papers selected for review were all qualitative and used a range of qualitative approaches:-

#### **2.1 Phenomenological analysis or IPA or existential Phenomenological Method**

( Bourland, 2011; Murray, 2004; Secrest, 1999)

**2.2** Grounded theory (Burton, 2000; Egbert, 2006)

**2.3** Naturalistic ethnographic enquiry (Davidson, 2008)

**2.4** Qualitative data/content analysis (Lynch, 2008; Northcott, 2011; [framework method with coding scheme] O’Connell, 2001; Stone, 2005; [open method] Thompson, 2009; [method not specified]).

**2.5** Case study and interpretation from records (Roman, 2006).

Interview lengths varied considerably from 25 minutes to 3 hours. Some studies were individual face to face interviews, and some were done in focus groups. Some were with SSs only, while others also included carers. One study (Davidson, 2008) included SSs with Aphasia and involved 8 hours of participant observation and videoing that the participants could then comment upon.

### **3. Participant characteristics**

Almost all the participants across the studies had experienced their stroke at least 1 year ago but the range extended to 23 years ago. Participants covered an age range from childhood up to 90 years old. Across the studies 66 men and 75 women were giving their accounts; one study did not specify the gender ratio, (O’Connell, 2001) with one of the studies specifically interviewing 22 younger women (Stone, 2005). The author considered the papers selected for their quality and contribution to the literature (appendix C).

### **4. Key themes across the papers selected for review.**

Further analysis for the review focussed on the themes that arose from the 12 studies. These themes and sub themes were collated across the papers (appendix D). Overall there were twenty one themes and sub themes across the papers. From this it was possible to focus on those themes which occurred most frequently in order to discuss and compare the results (appendix E).

From the 12 studies, the most frequent theme concerned ‘loss and maintenance of friendships and connection with others’ (n = 8).

This was followed by two themes each occurring within seven of the papers, ‘isolation due to losses in the social world’ which included loss of role and work: and ‘lack of social participation in the community and engagement in activity with others’.

The fourth theme (n=6) was more to do with the SS’s internal experience, how this had changed since the stroke and the whole process of self-hood after disability due to stroke.

The fifth most common theme concerned SSs reporting changes in emotional state or lability and emotional control.

### **Discussion of reported themes across the 12 studies.**

#### **Theme 1. Loss & Maintenance of friendships and intimate relationships, connection/disconnection with others.**

This superordinate main theme was the strongest one in the review, most frequently identified by eight of the twelve papers, (appendix D). It was also the most frequently identified by the highest quality papers within the review (Secrest, 1999; Murray, 2004; Stone, 2005; Davidson, 2008; Northcott, 2011;) (appendix C). These high quality papers had strong study design, described enabling SSs to take part in the research, and all excepting Stone (2005) had specifically included SSs with aphasia. This resulted in well-argued and evidenced themes from the accounts of SSs. Taken together these papers covered a wide range of ages and time since stroke ranging from 12 months to 34 years post stroke.

Divided into six subthemes, this theme comprised of relationships and communication ability/disability, unhelpful responses from others, concern about the reactions of others to

disability, the quality of communication with friends, relational ability affected due to stroke location and SSs relationship with their families.

### **1i Relationships and communication ability/disability**

In his study Murray (2004) clearly described SSs' multiple problems in social interaction, poor interaction with strangers, social withdrawal from friends and breakdown of familial relationships.

One of the main considerations within this theme was the primary importance of the mastery of language to be able to communicate in relationships. Reconnecting with life after stroke is hugely dependent on communication ability in order to maintain social participation. Loss of speech was mentioned more frequently and with more emotion than any other immediate repercussions of stroke and these difficulties with language ability were apparent very early on in any social interaction (Lynch, 2008). Stroke survivors with aphasia reported being particularly ridiculed and mocked by others (Northcott, 2011). In Davidson's study (2008) communication was observed to be central in everyday life and part of the nature of friendship connection. Domains of establishing communication 'greetings' were distinguished from 'engaging' in communication. Many SSs with aphasia could engage in saying hello but were not able to take the communication any further so many communications did not get beyond this and were incomplete. She went on to establish how social interaction necessitates a first stage of planning and negotiating such contacts followed by a second stage of going onto participating in social occasions. She showed that SSs with aphasia had many challenges in the effort needed in trying to communicate, resulting in a loss of their friends with a significant occurrence of communication breakdown. Davidson makes a number of recommendations in order to support aphasic difficulties such as: allowing SSs additional time to respond, encouraging the use of humour and the importance of developing shared interests.

### **1ii Unhelpful responses from others**

Unhelpful responses of others was cited as hugely challenging (Northcott, 2011) as SSs reported being abandoned, ridiculed, pitied, being told how to feel, patronised, and mocked. SSs told of this leading to shame and embarrassment.

Unhelpful help from others also included having speech corrected and unwanted assistance to get about, because of obvious physical disability (Burton, 2000).

### **1iii Concern about the reactions of others to disability**

In Stone's study (2005), young survivors of haemorrhagic stroke reported that others were not recognising that they had significant disabilities because they had apparently able bodies. These participants described avoiding situations because of others denying their disabilities but they also described hiding their difficulties too. Stone's study found that for the 22 women in the study there was a significant concern with the reactions of others, regardless of whether they struggled with cognitive or physical difficulties. Stone argues that the women in the study are all affected by a culture that supports simplistic understandings of how to read the bodily presentations of others. This cross cultural study lent credence to the possibility of this issue being cross cultural.

The primacy of relationships and how others saw SSs was woven throughout the transcripts in Northcott's (2001) study. The study described how through the perception of others a disability became a social reality. Concern was expressed by the participants that others would see them as unwell or disabled and that they would be dismissed, be less valued or pitied. Some reported feeling ashamed or self-conscious.

In Murray's study (2004), SSs commented on difficulties in forming new relationships as well as maintaining existing ones. Participants expressed a negative opinion of their own personal value and sexual desirability. Murray discusses how physical disability affects



the SS's view of themselves in the world. Murray recommended that counselling was needed which focuses on the acceptance of physical disability.

#### **1iv The quality of communication with friends**

Northcott (2011) found that the quality of a friendship prior to stroke helped to protect the relationship post stroke. Their study indicated that when the friendship was not activity based and the friend was living locally and mobile, friendships were more likely to be sustained. Supportive groups were seen as helpful and having a 'friends-based' network allowed for this to remain after stroke.

Friendship loss led to missed social activity and social events, close friendships had to change and the quality of the former relationship was a key factor in whether this occurred successfully. Where there was a loss of reciprocity in relationships a change of social identity occurred. It was clear however that SSs with aphasia did have more friends who no longer kept contact due to the difficulties with communication.

Secret (1999) concluded their study with a figural theme of connection and disconnection with others. Secret's understanding was that continuation of all types of relationships helped to bridge the schism in the discontinuity of the SS's life following stroke.

#### **1v Relational ability affected due to stroke location**

Egbert's study (2006) avoided aphasic difficulties as the participants were SSs with a right hemisphere stroke. It was expected that by focussing on this group that more subtle difficulties in communicative processes would have been highlighted. Disappointingly themes that arose from this study seemed very general and did not illuminate the kinds of communication difficulties described in the literature more generally. Relationship challenges in this study were described more globally as due to the loss of previously held roles, as participants now felt they were being an imposition on family and friends.

Friends and other family members were described as central resources for recovering SSs. 'Strong tie' relationships and the SS's own internal resources were seen as instrumental in them being able to adapt.

#### **1vi Stroke survivors' relationship with their families**

Lynch (2008) described 4 main themes within social relationships, commenting that stroke survival often results in breaks with significant others and can lead to lack of social support within SSs' own families. This study was carried out by collecting data from focus groups. The reported themes however were reported under headings that did not particularly illuminate this area. It seems likely that focus groups may inhibit SSs from discussing more personal experiences.

Thompson (2009) identifies over-protective care as one of the subthemes occurring in the pre and post stroke self. Over protective care from spouses contributed to SSs' increased anger and frustration. Emotional overprotection was also seen to demotivate and create dependence.

In Thompson's study, SSs recounted that their stroke had impacted considerably on their sexuality within their marriage, with husband and wife becoming more like patient and carer in their relationship. Women reported being disinterested in their outward appearance and there was a reduction or loss of sexual desire and intimacy following stroke.

#### **The quality of Themes 2, 3 and 4**

The following three themes occurred seven, seven, and six times respectively within the twelve papers (appendix D). Murray (2004) had found all these themes relevant, when in a good quality study he had sought SSs views on the meaning and experience of being a stroke survivor. From the viewpoint of the number of papers that demonstrated good study

rigour the theme most supported within these three is the theme of ‘social participation and community integration changes’. The paper which in the authors opinion is of the highest quality however, (Secrest 1999) did not specifically note themes 2 and 3 but did find ‘Pre and post stroke self , continuous/discontinuous self’ to be a strong theme when investigating post stroke quality of life.

## **Theme 2. Losses in social world, loss of role and isolation**

This second theme in the literature concerned the loss of social experiences within which people ordinarily participate and which keep us connected to those around us. It also describes SSs electing not to engage in social encounters because of the need to negotiate with others and the effort involved. This theme is made up of three subthemes ; ‘stuck in a cage’, ‘deciding’ to withdraw, and importance of role in society.

### **2i Stuck in a cage**

Burton (2000) described this well using the metaphor from the transcript ‘*Stuck in a cage*’. His study was illuminating as he interviewed six stroke SSs about their lived experience over time leading to a total of 73 interviews in all. A clear theme within social recovery was about being “Isolated or stuck in a cage”. “Cages ranged from their bodies to the hospital and their homes”. All references to this in Burton’s study were accompanied by frustration and anger. Waiting was a key feature in this isolation.

### **2ii ‘Deciding’ to withdraw**

Egbert (2006) described the isolation of the SS as somewhat of a choice that was being made. Many SSs wanted to remain in their own homes and would decline opportunities for social activities. One of the difficulties in Egbert’s study was that it included caregivers, so that much of what is quoted is from the more articulate caregiver. Egbert described how the survivor had to cope with new and often diminished vocational roles.

In Murray's study (2004) one participant, Ray, clearly expresses his dislike of crowds and his perception of his friends' level of understanding or ability to handle the fact of his stroke. Thompson (2009) describes how her participants saw home as place that felt comfortable and safe, avoiding the anxieties of crowds noise and pressure. But the accounts of this from the SSs are not very full. This may have been because the 25-minute interviews were not long enough to allow for a deeper exploration. For SSs with aphasia (Northcott 2011) described how the substance of friendship had been altered. SSs felt like they were less good company, and might now be boring. There was a reluctance to be seen as unwell or disabled. Going out to meet people could be a cause of anxiety and fear due to feelings of vulnerability, whilst staying at home could feel more secure.

For Roman (2006) grief and loss are one of the three defined themes outlined in his study. Of the two case studies he describes how one SS distinctly withdraws, mourning his loss of status, roles and language skills and this becomes a prolonged mourning.

### **2iii Loss of role in society**

In Murray's study (2004) there were also some SSs who had resumed previous social roles and who described getting back to work and feeling more "normal", but there were descriptions from Northcott (2011) of the SSs' loss of shared activities which included work, religious services, sport, cultural activities, etc. Younger survivors described feeling a great dislocation from their role in life because of the difficulty with cognitive processing and not keeping track of conversations.

### **Theme 3. Social participation/community integration changes. Being part, not being part of community. Engaging/not engaging in activity with others.**

This theme addressed the behavioural aspects of engaging and not engaging in social activity with others; and how this affected social and community participation. The

subthemes were; not engaging as before, being an imposition, and socially acceptable management of the body.

### **3i Not engaging as before**

Balances in family and social networks were disrupted and informants expressed difficulties in redefining their perceived contribution to social and family life. Burton (2000) heard how SSs were in a process of continuous appraisal and reappraisal of their social role. SSs reported that it was the social meaning of activities that was missing. In order for older SSs with aphasia to participate in leisure activities and other daily activities they needed to engage in communication situations outside their home. However older SSs with aphasia were observed to watch TV alone or with family, having limited involvement in sports or hobbies (Davidson 2008). Davidson showed that SSs with aphasia did more listening at social events, even when they were with other SSs.

### **3ii It's too difficult, they won't understand, I am an imposition**

SSs described their additional need for help as something that could be too difficult to explain or negotiate. Dependence could be felt as an imposition on family or friends (Northcott 2011). Stone (2005) recounts how SSs would not explain their absence at social gatherings because they did not think that others would understand their difficulties. She comments that it can be difficult to negotiate social expectations based on an apparently able body.

### **3iii Socially acceptable management of the body**

Murray (2004) described how the socially acceptable management of the body was important in self-identity, citing the work of Goffman (1963) and arguing that for people with disabilities their ability to achieve this is often compromised. One participant in his study described how a bus driver refused to let him on the bus because he accused him of "*being pissed*" – when from his point of view he was trying to be independent and go out

on his own. Murray describes how aids to walking and moving can be a possible barrier to social interaction as SSs felt that it can affect self-confidence to use a walking aid. Northcott (2011) found in his accounts that poor mobility could also be made more difficult by environmental barriers.

#### **Theme 4. Pre and post stroke self. Continuous/discontinuous self; the dichotomy.**

##### **Contrast of previous life. Loss and grief. Disrupted embodiment and loss of self.**

Although this theme is described as fourth in the rank order, the theme is a very strong one. It focussed more about feeling and the meaning of self and self in relation to others as a post stroke life emerges. These themes are; unfamiliarity of new life, stroke survival, disrupted embodiment, and continuous/discontinuous self.

#### **4i Unfamiliarity of new life**

Burton (2000) called this “reflections on previous life” – “even when specific activities had been remastered the social manifestation of those activities appeared to be missing”. Informants felt that their new lives were essentially unfamiliar and the passing of time didn’t necessarily alter the experience of these effects.

#### **4ii Stroke Survival**

Egbert (2006) called the personal characteristics that allowed the SS to meet the daily challenges of coping with stroke, ‘personality strengths’. These strengths that she heard described as being helpful were: patience, motivation and determination, a positive attitude and humour. Egbert describes these attributes as internal resources which allowed the SS to go on and meet the daily challenges of coping with stroke. She gives examples from her participant scripts of how these attributes get played out in more successful stroke survival. She understood that these internal strengths ‘are paramount’ and a far more important focus for support, rather than focussing on physical functioning. She concludes

that these strengths need to be supported in order to increase positive outlook and determination.

#### **4iii Disrupted embodiment**

There were many quotes from SSs' personal accounts in Murray's paper (2004). Part of their loss was expressed as a disrupted embodiment.

#### **4iv Continuous/discontinuous self**

Murray (2004) described the loss of personhood, when participants described a profound loss of self or part of self and continued estrangement from the person they were.

O'Connell (2001) reports this theme as 'end of life as they knew it, everything switches off'. SSs felt that they had to start again. The quotes in this study are very thin however and don't really offer a rich explanation of what this means.

The main theme from Roman's work (2006) was the 'continuous / discontinuous self'. He worked with 2 SSs. One SS maintained a sense of continuity through change and the other did not; the one that did was able to reconstruct himself during recovery and this was an on-going process. Years of grief was involved for both SSs even the one who adapted 'well'. Roman saw this as a loss-oriented and restoration-oriented coping process. He found that internal attitudes to change featured strongly in the ability to grieve and adapt, just as Egbert (2006) had.

In Secrest's (1999) ground and figure analysis, SSs described feeling disabled in spite of others' perceptions. All of Secrest's themes served to define the SS self, making the study much more about internal experience. The 'ground' for the experience of surviving stroke was understood as being loss and effort. 'Loss' included all that had been lost from memory to dependence. The second ground experience was 'effort'. Effort leads to fatigue and frustration with everything being so very time consuming; it took so long to

walk for example or to think about what to say. Figure themes are very personally focussed: independence, in and out of control, discontinuity and continuity in experience of self, sameness and disruption. This paper provides a very good structure for mapping out the complexities of all the challenging facets of stroke.

#### **Theme 5. Emotional responses of stroke survivors – emotional recovery.**

This final theme was contained within five of the twelve papers. The author considered that two of the papers supporting this theme were too broad conceptually, did not explain analysis or selection very thoroughly and had a fairly poor discussion (O'Connell, 2001; Egbert 2006). Burton (2000) included this theme, but thematic analysis from this study did tend to be rather broad and overinclusive. The theme was included however because of its position in the ranking order and because of strong evidence from the work of Murray (2004) and Northcott (2011); both papers demonstrating good standards of qualitative research.

This theme itself, describes the focus on identifying particular emotional responses and the changes in emotionality that have occurred since the stroke. The two subthemes within this are: emotional responses and loss of emotional control.

#### **5i Emotional Responses**

Burton (2000) reported a number of emotional themes, including uncertainty and fear and SSs having increasing feelings of less control during different transitions in their recovery. In Burton's study participants reported that loss of control could be dealt with as recovery progressed by focussing on more positive aspects of their life which they did have control over. Control was an issue when feeling dependent on others. Hope was a theme early on in recovery. Anger and frustration were expressed when making comparisons with pre-stroke life and those with physical problems portrayed anger and frustration more strongly. His study did not include SSs with aphasia. The diversity and fullness of the more



emotional accounts may well have been a result of the on-going interviews allowing for greater depth of expression.

Egbert (2006) describes particular emotional challenges from his SSs accounts as being anxiety, frustration and depressive symptoms related to loss of functioning. In this study, fatigue featured a lot as a contributor to these feelings. O'Connell (2001) discusses depression and suicidal thoughts and Northcott (2011) discusses depression due to isolation from friends. Thompson (2009) made specific mention of anger proneness and irritability, and frustration at being unable to perform activities of daily living. SSs portrayed themselves as useless, a burden and lazy.

### **5ii) Loss of emotional control**

Murray's study (2004) was the main one that articulated the difficulties SSs have with emotional responses. From his interviews, the invisibility of emotional responses was a key and significant part of experienced disability. SSs described their emotional changes as complex and recognised that other people might describe their emotional responses as inappropriate, which disturbed them. There were many examples given of loss of emotional control in the paper and a reduced capacity to interpret and respond to other people's emotions appropriately was well described. Study participants described having a loss of control over emotional displays and engaging in inappropriate expressions of emotion that they found disturbing and unacceptable. In Murray's research (2004) the unseen emotional changes that accompanied a stroke were remarked on as more disabling than some of the physical disabilities. SSs felt a need to have their problems acknowledged by others and this kind of difficulty was very hard to manage. Thompson (2009) described participants telling how they were not able to control outbursts although she did not identify this as a theme. In Stones (2005) study she describes "subtle cognitive challenges can mean that participants are easily misunderstood and periodic energy deficits

can make for inconsistent social behaviour or can make it impossible to meet common expectations of acceptable sociability” but doesn’t give any particular examples.

## **Summary**

This review selected twelve papers from the available literature that had a particular focus on longer term SSs’ own accounts concerning how their stroke had affected them emotionally and socially. These studies yield a wealth of data on the more social and emotional effects of being a SS. Of particular interest are those that have focussed on aphasic SSs in order to help understand and assist communication challenges within social contexts. The studies as a group provide specific information about the experience of social disconnection, loss and isolation that can occur. They illuminate the considerable personal impact on the SS’s self-perception, adjustment and ability. For the SS, being a part of the social world and engaging in social activity is an important mirror for self-definition and self-esteem, and considerable self-worth is needed in order to re-enter the world following stroke and deal with the multiple challenges that affect social communication. The studies have shown that having disrupted social and emotional engagement resulted in a sense of disembodiment, loss, and a disconnection with self. One particular study (Murray, 2004) was also able to highlight specific emotional experiences that occur following stroke and the problems with emotional self-regulation and emotional response which is so vital in sustaining successful interpersonal relationships. Participants in these studies describe the necessity for the physical and emotional strength to combat fatigue and disability which is based on social support, when the SS can feel accepted and understood regarding more obvious as well as subtle disability. SSs have expressed the importance of mobilising personal strength to regain a sense of selfhood and work with the residual effects of stroke and their struggle in regaining a post-stroke sense of self.

The themes within the studies have shown themselves to be often highly interrelated even when the lens of the researcher has a different focus and study design. Some participants were given far more time to express more about the often contradictory positions that they were still struggling with many years post-stroke.

### **Future research**

More research is needed into the process of supporting stroke survivorship longer term, particularly regarding their emotional and relational abilities; finding out what support, skills and knowledge are needed in order to help shape their future lives in a meaningful way. More evidence is needed regarding the best ways to mobilize varying types of support through clinical and community programmes that keep the SS central to the process of community integration. Research investigating ways to assess SSs' internal resources such as communication competence, or humour, would then help to enable more targeted interventions. Interventional programmes could also be researched to help facilitate best practice for occupational participation.

There is a need to include more SSs with aphasia and those with more severe stroke symptoms who typically do not engage in stroke research. Qualitative interviews need to be long and open enough to discuss more personal themes.

Extended inquiry into friendship interactions is needed and research to focus on those features that facilitate positive conversations and develop training for friends of SSs with aphasia. Research on further understanding the impact of friendship changes on well-being and quality of life (QOL) and the impact of those qualitative changes in friendship relationships would help to support communication programmes. Further research is needed that works up measures of stroke-related QOL capturing the important influence of stroke upon social relationships, support from others and communication in addition to social function or activity limitation.

## **Conclusions**

This review has sought to locate and present peer-reviewed literature concerning longer term SSs' accounts of social and emotional challenges after stroke. The 12 studies that were identified showed the complexity of stroke recovery as SSs view it and how this has affected their stroke survivorship. The studies have shown that the difficulties/disabilities continue for many years and that learning to live with them and adapt continues for a very long time, affecting the SS's role in the world, their social and support structures as well as their emotional abilities and personal identity. Although the papers have a variety of foci, there are similarities that serve to underline the importance of personal meaning in stroke survival, in being able to communicate as needed and in being accommodated and accepted by others. As qualitative studies they do highlight the range of possible psychosocial difficulties that SSs say affect them in stroke survival and help to illuminate the path of understanding in stroke survivorship for those that are alongside them in their recovery.

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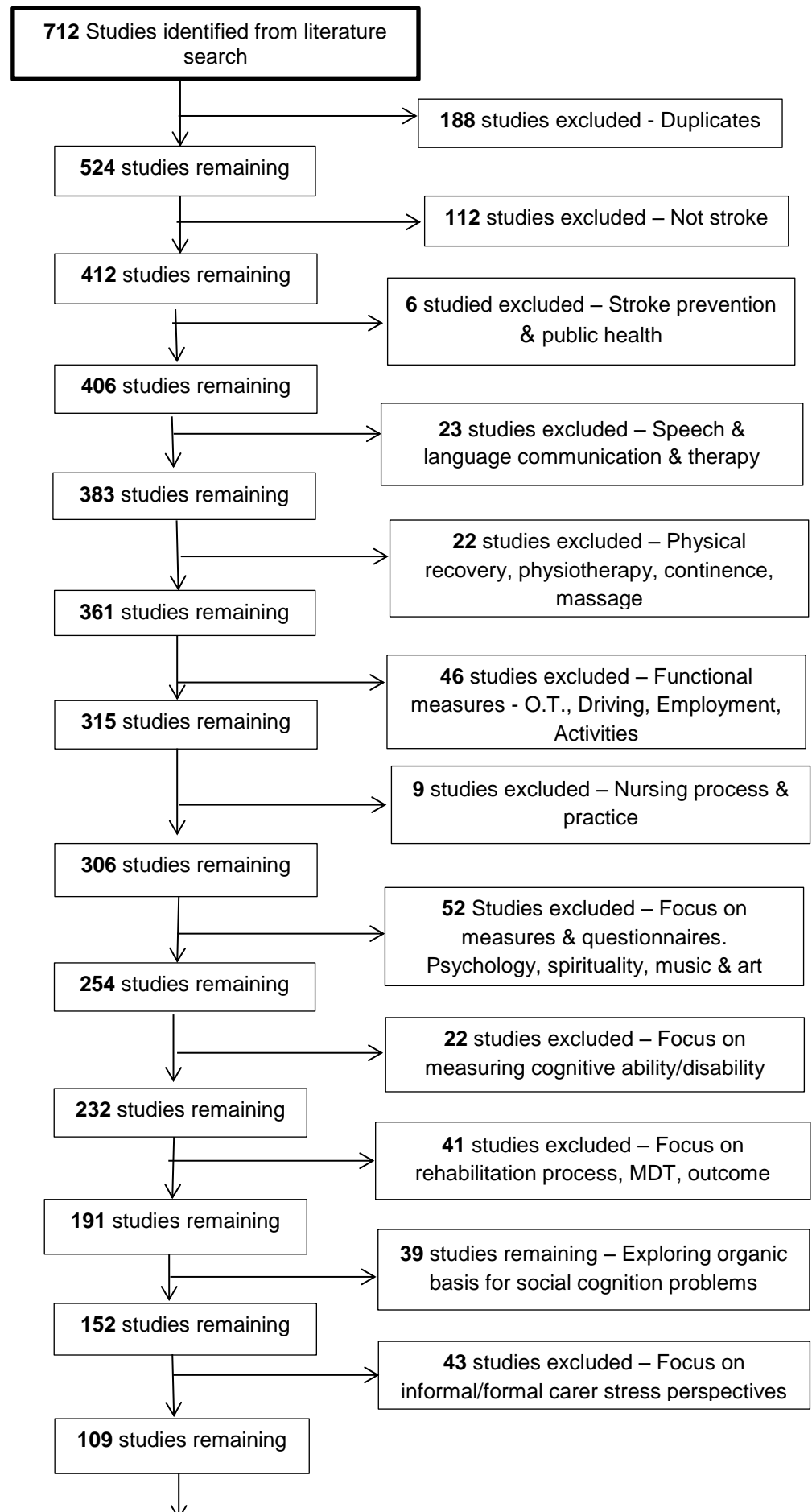


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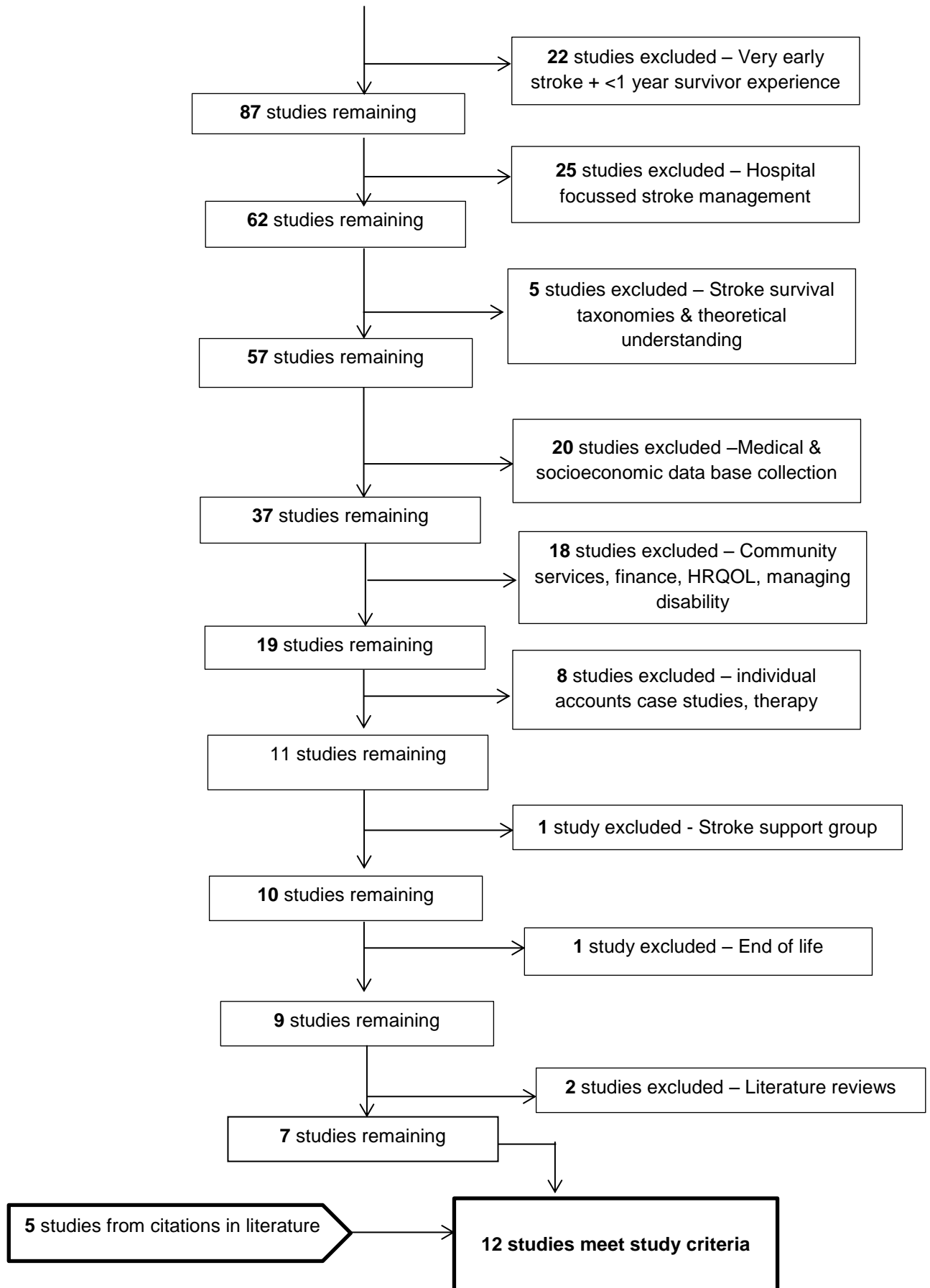
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## Appendix A – Literature Review Exclusion Process (1)



## Appendix A – Literature Review Exclusion Process (2)



## Appendix B Literature Search Key Papers Table

Longer term Stroke survivors accounts of social and emotional challenges after stroke – a review of the literature.

Main author and title of paper	Recruitment strategy 1.inclusion & 2.Exclusion criteria	1. Location, 2. Participants, age, ethnicity etc. 3. Years post stroke	Method & Design Methodology of the interviews and other observational techniques	1. Focus/philosophical position/purpose. 2. Analysis 3. Limitations	Key themes identified / results
<b>1.Bourland E.L.R.;</b> Neville, M.; Pickens, D. (2011) <i>“Loss, gain and the reframing of perspectives in Long term stroke survivors: A dynamic experience of quality of life”</i> Top Stroke rehabilitation 2011;18 (5);437 – 449.	Recruited from local stroke support groups and community OT’s. <b>1.</b> Between 58 – 80 years. Be min 24 months post stroke. English speaking. <b>2.</b> Not specified.  <b>IV=Interview</b> <b>OT=Occupational Therapist/Therapy</b> <b>QOL=Quality of Life</b> <b>S=Stroke</b> <b>SS=Stroke Survivor</b>	<b>1.</b> Texas USA <b>2.</b> 3 male. 3 female- 58 -79. 4 married; 2 working FT; 1 divorced; 3 retired from stroke; 1 widowed; 1 retired pre stroke; 5 Interviewed at home; 1 at work <b>3.</b> 21 months to 11 years	Each participant interviewed 1 hour x2. First interview 1. “How do you define quality of life?” 2. “Do you think of quality of life differently now that you have had your stroke?” Transcribed and analysed before 2 <sup>nd</sup> IV. Journal to write in between interviews; for questions or thoughts re study. 2 <sup>nd</sup> ; 30 mins. Usually occurring 1 week after first. Used to clarify	<b>1.</b> The lived experience of quality of life in long term SS’s Quality of life study using the WHO lens of function, disability and participation; Model of Human Occupation and shifting perspectives in Health Model To increase construct validity. <b>2.</b> Phenomenological study interviews Audio recorded and transcribed. Thematic analysis performed. Themes discussed with participants. Nvivo research software utilized. Research team Analysis. Attempted end	<u>Quality of life is doing what you want to do.</u> Activity Loss “I can”; “If I want” <u>It makes me feel like a human again</u> Awakening “That’s what I miss”; “Reality comes to your world”  Overall emphasis on social participation. Participating in valued activities and able to continue to do this post stroke resulted in better QOL.  Changes in personal identity understood as result of lost roles. Discussion of the model of human occupation and shifting perspectives model and its applicability to the results. Recommend intermittent longer term intervention to support adaptation and changing needs over time.

			answers from first lv. and explore further – saturation data.	checks with participants <b>3.</b> 2 participants returned the diary. Larger and more varied participants would have strengthened results. Personal subjects not necessarily explored. No aphasia participants, no severe stroke.	
<b>2.Burton C.R. (2000)</b> <i>"Living with a stroke: a phenomenological study"</i> Journal of Advanced Nursing 32(2) 301-309.	lv initially in hospital following S. <b>1&amp;2.</b> free from dysphasia, no history of depression, no evidence of cognitive impairment, no other significant medical history	<b>1.</b> North west England <b>2.</b> 1 <sup>st</sup> stroke. 6 participants. 4F, 2M; 52-81yrs; 2 employed; 2 married, 2 widowed, 1 divorced, 1 single. All at home. <b>3.</b> min 12 months post stroke	Initial interviews informal. Asked to tell stroke story. Follow up interviews, to explore earlier issues. Further data collected at monthly intervals min 1 year. Total interviews = 73. Mean lv length 35 mins. Audio recordings and transcripts. Maintenance of a researcher log journal.	<b>1.</b> identify the lived experience of recovery from stroke. To develop reference frame for stroke survivor evaluation of recovery. To expand out from professional interpretations of recovery <b>2.</b> Grounded theory. Analysis ongoing throughout study. Process explained, research log kept and discussed with peers. <b>3.</b> Small number of informants but longer follow up may allow for the transferability of themes to wider services.	Content analysis – themes and subthemes. <u>Issues in physical recovery</u> Initial personal experiences of a stroke. Early recovery. Slowing down. New challenges. <u>Issues in emotional recovery</u> Uncertainty. Hope. Loss of control. Anger and frustration. <u>Issues in social recovery</u> Changing roles. Isolation. Reflections on previous life.

<p><b>3.Davidson</b> Bronwyn, Louise Hickson, Tami Howe, Leanne Togher, and Linda Worrall (2008). <i>“Social participation for older people with aphasia: the impact of communication disability on friendships”</i>. Topics in Stroke Rehabilitation. 15.4 p325</p>	<p>Older Australians Recruited from rehab units and community based clinics. 1 .English as first language. CVA at least 6 months prior to study. Diagnosis of A (Western Aphasia Battery). 2. Dementia, dysarthria, uncorrected hearing loss, neurological disorder, serious illness.</p> <p><b>P= Participants</b> <b>OP = Older People</b> <b>A = Aphasia</b> <b>F= Female</b> <b>M= Male</b> <b>IV = Interview</b> <b>Obs= observations</b></p>	<p>1. Australia. 2. <i>Phase 1</i>. Older Australians, living independently 15 with chronic A (3 under 12 mths) and 15 matched controls (gender, education, living situation) without A. Mean age 71.60 years A, 71.27 control. Mean 7-15 years education. <i>Phase 2</i>. 3 A P’s from 15 in phase 1; 2F, 1M.</p>	<p>Pilot study 2 A and 2 non A OP determined obs. i) schedule and coding sheet. Reliability checks between 2 SLT researchers (coders). <u>Phase 1</u>. 8 hours total obs per P. ii) Field notes. Iii) 5 day structured forms of communications diary). <u>Phase 2</u>. Collective case study – friendship conversations iv)Video recording v) Video Stimulated recall, transcribed verbatim. Use of non verbal, gestural response and visual scales.</p>	<p>1 .Naturalistic, ethnographic enquiry. Describe everyday communication with friends for older people with and without aphasia &amp; examine the nature of real life friendship conversations involving a person with aphasia. 2. Triangulation from participants. Summary of key findings. Interpretative analysis of common themes in social communication across friendship. 3. No feedback from participants on the impact of the observer. Study context specific and not necessarily transferable to other contexts.</p>	<p>OP with A communicated with a smaller number of others. Total number of friends observed, Non A = 52 friends, A = 20. <b><u>Everyday communication Domains For SS with Aphasia</u></b> (obs and diaries) 1. Establishing communication: greetings more prevalent 2. Engaging with others: more passive and listening. 3. Leisure participation: watched TV alone or with family more. 4. Planning and negotiating: less writing, less planning and organising. 5. Incomplete communication: unsuccessful with family and others. <b><u>Conversations between friends</u></b> 1. The need for additional time to respond. 2. The role of humour integral. 3. The importance of shared interests.</p> <p>Illuminates factors relating to the centrality of communication in friendship. Sheds light on everyday social communication for SS with A and the impact of this on conversations between friends. Programmes needed that address social participation issues for SS with A. assisting family and friends of SS with A.</p>
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<p><b>4.Egbert, Nichole, Koch Lynn, Coeling Harriet, Ayers Denise. (2006)</b></p> <p><i>"The role of social support in the family and community integration of right-hemisphere stroke survivors".</i> Health communication, , 20, 1, 45</p>	<p>SS from RH stroke &amp; CG. Recruited through SS support groups, and regional stroke conference.</p> <p><b>1.</b> RH stroke, left hosp. min 6 months, fluent in English, CG in the home, willingness to participate in 1-2 hours IV.</p> <p><b>IV=Interview</b>  <b>SS= Stroke Survivor</b>  <b>RH= Right Hemisphere.</b>  <b>CG= care givers</b>  <b>F=Female</b>  <b>M=Male</b>  <b>ADL=Activities of Daily Living</b>  <b>HCP=Health Care Providers</b></p>	<p><b>1.</b> Ohio, USA. Rural, urban and suburban communities.</p> <p><b>2.</b> 12 RH SS and 13 CG. 2F, 10M. Mean age 59.67 years. 4 employed, 4 retired, 4 not working. SS IV'd concurrently with CG and independently. IV at home excepting 2.</p> <p><b>3.</b> Not described. Only descriptions of life change.</p>	<p>Same IV protocol used for SS and CG. General open ended questions with probing. IV 60-90 mins. Audiotaped and transcribed verbatim.</p>	<p><b>1.</b> exploring and developing social support theory for SS reintegrating into family and community. Drawing on conservation of resources theory.</p> <p><b>2.</b> Grounded theory Qualitative Research Design. 4 experienced interdisciplinary researchers coded transcripts. Codes revised and audited continually through constant comparison process. Major themes and interrelationships coded across categories. Corroboration data gained from accounts of SS and CG.</p> <p><b>3.</b> Not discussed.</p>	<p><u>Themes re Challenges</u></p> <p>1.Physical impairments,  2.cognitive/perceptual challenges,  3.Emotional difficulties (including isolation declining social activities, sensitivity to emotions, crying, more anxious, depressed, angry.4. ADL  5.Relationships (includes being an imposition on family and friends, challenges to previously held roles  6.vocation 7.financial challenges.</p> <p><u>Themes re Resources</u></p> <p>1.External formal resources Informational support, emotional support from HCP.  2. External informal resources  3. Internal resources. Personal characteristics for coping – Motivation and determination. Humour.</p> <p><u>Relations between external and internal resources</u></p> <p>Most important, strong tie external resources and SS internal resources.</p> <p>Quality of SS internal resources crucial to community integration regardless of level of disability and this is closely aligned with being accepted within vital community networks.</p>
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<p><b>5.Lynch</b> Elizabeth B Et al. (2008)  <i>"A qualitative study of quality of life after stroke: the importance of social relationships"</i>  Journal of rehabilitation medicine 40:518 – 523.</p>	<p><b>1</b> .S.S.18+years English speaking. Not in hospital. Able to engage 60 - 90 mins discussion. Caregivers  <b>2.</b> Severe aphasia, chronic fatigue.</p> <p><b>QOL=Quality of Life</b>  <b>CG=Caregivers</b>  <b>SS=Stroke Survivors</b></p>	<p><b>1</b> .Chicago, Illinois, USA.  <b>2.</b> 9 long term SS, 5 men and 4 women Mean age 54.7 years. 8 African American, 1 caucasian. 4 married, 3 single, 1 widowed.  <b>3.</b> Mean post stroke years 11.9. &amp; 6 caregivers</p>	<p>Round table Focus groups. Firstly how QOL had been affected; then 17 Open ended questions re: changes in specific dimensions of QOL. More focus on themes that emerged from the general query about QOL.</p>	<p>1. Importance of social functioning to QOL. Identifying dimensions of QOL .  Developing a disease specific HRQL measure.  <b>2.</b> Audio recordings, qualitative data analysis used. Themes identified where coding overlapped sufficiently.  <b>3.</b> Small sample group. Participants in a focus group context may be less likely to vocalise disagreement. Focus groups used to generate hypotheses, not test them.</p>	<p>For SS – <u>Majority of themes referred to changes in social relationship.</u>  1. Maintenance of critical social relationships.  2. How friends and family supported or didn't following stroke. Extensive discussion re: those who didn't and stories of this with other SSs. (CGs– when prompted spoke of stroke bringing closeness).  3. Loss of speech and extreme emotional reaction to this; affecting self-esteem and confidence.  4. Independence. Appreciating the support while feeling uncomfortable with dependence. Cause of mood disturbance. Caregivers struggle with SS ambivalence about this.  <u>INDIVIDUAL THEMES (NOT SOCIAL)</u>  seen more as personal  *Coping mechanisms. Discussion of strategies for coping with stroke impact.  *physical functioning &amp; independence. How managed to overcome physical challenges. (CGs discussed social relationship problems due to changes in social roles such as the inability to return to work).  Need interventions with an Emphasis on acceptance and sense of belonging, to increase positive</p>
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					outlook and determination. Need emphasis on relationship building to increase likelihood of community integration. Key Internal resources paramount; like communication competence.
<b>6.Murray C.D. and Harrison B. (2004)</b> <i>"The meaning and experience of being a stroke survivor: and interpretative phenomenological analysis."</i> Disability and rehabilitation 2004; vol 26; No 13 808 -816	Contacts through National Stroke Network. <b>1.</b> Stroke survivors. At least 2 years post stroke. <b>2.</b> No stated exclusion criteria.	<b>1.</b> Liverpool UK <b>2.</b> 5 individual face to face interviews. 5 email participants. Mean age 48.8 years. 6 divorced, 2 widowed, 1 married, 1 single. 4M; 6F. <b>3.</b> Average 9 years post stroke.	Face to face Semi structured interview schedule: life before the stroke, recollections of the stroke, life after stroke, the future. Approx 1 hour. Email exchanges with set of provisional topics involved sequential exchanges over average 6 weeks. Average of 8.4 written exchanges.	<b>1.</b> Explore the concerns perspectives and experiences of survivors following stroke. <b>2.</b> (a) audiotape of face to face IV's. (b) email data. Analysis using IPA. <b>3.</b> No limitations stated.	<b>1.</b> <u>Disrupted embodiment and loss of self.</u> "loss of me". Self estrangement. <b>2.</b> <u>Invisibility of emotional difficulties.</u> Emotional responses inappropriate. Crying unexpectedly. Key and significant aspect of their experienced disability. Loss of control over appropriate expression of emotion disturbing and socially unacceptable. <b>3.</b> <u>Gender romance and sexuality.</u> Lack of self confidence and negative self evaluation. <b>4.</b> <u>Social interaction.</u> Negotiating public perception of physical disability. Social exclusion/social withdrawal/more tension in relationships. Expression of emotion for SS can be

					disabling. Post stroke counselling is needed for romantic and sexual relationships, and for familial relationships and CG's.
<b>7.Northcott, S. &amp; Hilari, K. (2011)</b>  <i>"Why do people lose their friends after a stroke?"</i>  International journal of language and communication disorders, 46, 5, 524 - 534	Recruited from 2 acute stroke units and followed for 6 months. <b>1.</b> 18+, first stroke, SS with A preferentially included. <b>2.</b> Other severe co morbidity, too unwell to give consent, not living at home prior to stroke, known history of Mental Health problems or cognitive decline or non English speaking.  <b>F=Female</b> <b>M=Male</b> <b>P=Participants</b> <b>A=Aphasia</b> <b>NIHSS=National</b>	<b>1.</b> London UK <b>2.</b> Purposefully & robustly sampled to optimise diversity and range of characteristics e.g friendship networks, age, gender and ethnic background, stroke severity, mobility, communication, stroke type. N=29 18-90 years. 12<65yrs, 12F, 17M. NIHSS score 2 mild, 21 severe, mean 9. 10 P had A. <b>3.</b> Generally 1 year post stroke range 8-15 months.	Topic guide used re: friendship patterns, role of friends and social support pre and post stroke. Audio tape recorded. IV mostly at home. Field notes after each IV. Experienced SLT interviewer trained in qualitative techs. 2 early IV evaluated by senior researcher. Supported communication provided. IV's transcribed verbatim.	<b>1.</b> Perceived causes of friendship loss; what factors protect friendships; how perceived by the individual SS. <b>2.</b> Analysis using "framework method" Initial themes and concepts developed though data review. Thematic index created. Thematic charts constructed. Matrix created from theme and case based analysis. Collaboration with senior researcher to minimise bias. <b>3.</b> Timing of study may have precluded proper investigation of the role and value of new friendships formed after the stroke e.g. through stroke clubs; and friendship change.	<u>Themes re; causes of friendship loss after stroke</u> 1. Loss of shared activities 2. Reduced energy levels 3. Poor mobility and other physical symptoms. 4. Unhelpful responses of others; including ridicule, pity or patronisation. 5. Environmental barriers. 6. Aphasia (all who had lost their entire friendship network since S had aphasia). 7. Changing social desires," I seem to be closing in on myself". Might now feel boring. Reluctance to others seeing them unwell or disabled, vulnerable. Social gathering stressful. Loss of reciprocity. Re-evaluation of social world. <u>Themes re: Factors that protect friendships</u> 1. Feeling close to a friend. Quality of pre stroke friendship. 2. Distance 3. Availability of friend. 4. Not activity based prior to stroke.

	Institute of Health Stroke Scale IV=interview SLT= Speech and Language Therapist			Only 2 P's were under 50 years. Friendships with paid contacts not analysed in the paper. Findings may not be generalizable to other contexts	5. Regular supportive groups. 6. Family friends 7. Having a 'friends based' social network prior to the stroke. Friendships and maintaining them are as likely to be due to internal as external factors.
<b>8.O'Connell, B.; Hanna, B.; Penney, W.; Pearce, J.; Owen, M.; Warelow, P. (2001)</b> <i>"Recovery after stroke a qualitative perspective"</i>  Journal of qualitative Clinical Practice, 21, 120-125	Recruited by "convenience" and snowballing. Newspaper advert, support groups. <b>1.</b> Assessed for being orientated to time place and person <b>2.</b> Not stated  <b>SS=Stroke Survivor</b>	<b>1.</b> Victoria, Australia. <b>2.</b> 40 participants. Mean age 58.4 years and ranged from 20 – 89. <b>3.</b> Mean time since stroke 4.5 years. Range 2 – 180 months.	5 Focus groups semi structured 60 – 90 min interviews; 3 with SS's, one with carers and one with key informants. Part of larger study. Survey instruments.	<b>1.</b> Eliciting strengths and weaknesses from SS re: living in the community after a stroke. <b>2.</b> Research analysed using NUD*IST data management system. IV audiotaped and transcribed. Content analysis. Major themes extracted – <b>3.</b> Generalisability not claimed and biases acknowledged.	Themes: <u>End of life as they knew it;</u> <u>everything switches off.</u> <u>Life after stroke</u> Positive and negative experiences <u>Losses and frustrations</u> <u>Emotional and social issues</u> <u>Carers</u>

<p><b>9.Roman MW (2006)</b> The process of recovery: a tale of 2 men. Issues in Mental Health Nursing. 27:537-557.</p> <p><b>P=Participants</b> <b>M=Male</b> <b>Hemi= Hemisphere</b> <b>A= Aphasia</b></p>	<p>Part of larger multi-case, case study of SS's. 3-10 years post stroke. Had participated in a university based transdisciplinary programme for recovery and reintegration into life.</p>	<p><b>1.</b> Tennessee USA <b>2.</b> 2 case studies. First, 45year M; aneurysm in artery affecting left hemi. Non fluent Brocas A, speech apraxia. Second - 79year M with severe A. <b>3.</b> 5 years since stroke; 8 years post stroke.</p>	<p>A series of face to face IV's gaining first hand retrospective accounts of the P's. Research questions – how does one recover after stroke, what is the process? How is a sense of normality restored? How is ones sense of self involved?</p>	<p><b>1.</b> Person oriented qualitative approach, within a biopsychosocial framework. <b>2.</b> Time series graphic displays, direct interpretation, pattern analysis. Archival time stable records, and individual case analysis. Rigour through audit trail, and P checking of manuscripts. <b>3.</b> Only 2 case histories.</p>	<p>2 studies considered the loss of language which both men considered central to their concept of self. Repairing of the relationship to pre stroke self. Interrelated aspects salient to recovery in many adult circumstances. (a) The continuous/discontinuous self. (b) Ones worldview on change. (c) Grief and loss. More applicable of the post stroke work than depression. "Mastery despite deficit" Grief for past self. Loss orientated/restoration orientated coping processes . Relationship with self affects relationships with others.</p>
<p><b>10.Secret J.A. (1999)</b> <i>"Continuity and discontinuity: the quality of life following stroke"</i> Rehab Nursing 24:6 240 - 246</p>	<p>Purposive from 3 freestanding inpatient rehab units <b>1.</b> willing and able to articulate experiences, primary diagnosis of stroke, completed inpatient rehab, at least 6 months post stroke <b>2.</b> Not specified</p>	<p><b>1.</b> South east Tennessee. USA <b>2.</b> 14 stroke survivors, 7M and 7F, Caucasian, mixed stroke locations. Aged 40-93 median age 67years. All at home, all had experienced neurological deficits. 8 some degree of aphasia, 3 marked. <b>3.</b> 9months to 23</p>	<p>One Interview 1 – 1.5 hours, focus on unreflected experience. IV in homes or offices. "How would you describe specific experiences since your stroke that stand out for you?" Probes as needed.</p>	<p><b>1.</b> Quality of life study. Following rehab. Thematic structuring of participants experience. <b>2.</b> Existential phenomenological method. Interpretation of the communicated experience. Use of multidisciplinary research group for analysis. Focus of figural analysis for survivor, against the ground of</p>	<p>Grounded Theme of <u>Loss and effort</u>.- which permeate all the other themes. Loss is the condition of effort and effort is the indicator of loss. Focal Interrelated themes – <b>1.</b> <u>Independence-ability/dependence-disability</u>; <b>2.</b> <u>being in control/out of control</u>. Unpredictability of body; speech etc. <b>3</b> <u>Connection/disconnection</u> with others. Aphasia. Unhelpful help. Not whole. Primacy of relationships for feedback.</p>

		years post stroke.		the event. Bracketing (bias reduction) employed, researchers interviewed and critically analysed. Selected transcripts audited. Validity gained from showing participants thematic structure. <b>3.</b> Bias addressed.	<b>4. Continuity and discontinuity in the experience of self</b> Beneficial changes in life style/values. Invisible disabilities. Links all these themes for experience of QOL. Individual meanings far more important than objective deficits or disability. Nurses need to concentrate on the meaning of activity etc. for the individual.
<b>11.Stone S (2005)</b> <i>"Reactions to invisible disability; the experiences of young women survivors of hemorrhagic stroke"</i>  <b>S=Stroke</b> <b>HS=Haemorrhagic stroke</b> <b>SS=Stroke Survivors</b> <b>M=male</b> <b>F=female</b> <b>QOL=quality of life</b> <b>Hpg=Hemiplegia</b> <b>I=Invisible</b> <b>A=aphasia</b> <b>STM=short term</b>	Recruited by convenience and purposive sampling internet support sites, newsletter, Hospital database. GP's. Part of Larger study - narrative collection from F HS SS of < 50yrs.. <b>1.</b> HS at least 2 years ago; before age 50. Had subjective invisible, residual difficulties.	<b>1.</b> Across 4 countries Canada, Scotland, US, England <b>2.</b> 22 women. 21 Caucasian, 2 Jewish. Age range 19-57, S age 8-49. Most had ruptured aneurysm and surgery. I=partial Hpg; A; poor STM; visual problems, epilepsy; significant fatigue. <b>3.</b> 3 to 34 years post stroke.	IV Open ended and semi structured, 1 – 3 hours in length generally at home. Asked about experiences surrounding actual event and recovery, with the medical profession, being or not being recognised as disabled, self image, relations with others, perceptions of S meaning within life. Same interviewer – who was a SS from 11 years old. Care taken not to lead	<b>1.</b> Cross cultural study of Women only Younger SS of HS; including S in childhood. Meaning of their SS experiences in their life context. What are their concerns over time and QOL. Understanding less obvious disability in a social context. <b>2.</b> Transcript reviewed, each participant given IV copy to comment on. Author and research assistant developed Open Coding scheme developed for each part of the interview. Data organised using QSR NUD*IST <b>3.</b> Small sample, but	<u>The significance of age-But you're so young!</u> A) Participant reactions B) Reactions of others  <u>Must disability always be visible? the significance of appearance</u> A) Doing and explaining the unexpected B) Denying the presence of (physical & cognitive)disability.  1. P's acutely aware of not always being able to meet the expectations of others. Huge concern with the reactions of others. Traditional socialisation for women to be attentive to the opinion of others. This concern remained regardless of time since stroke. 2. Others forgetting or denying that SS's have any disabilities

<b>memory</b> <b>P=Participants</b>			from own experiences.	diverse. Not otherwise discussed.	whatsoever. Overlaid with P's own comparison of her invisible difficulties with the visible difficulties of others.
<b>12.Thompson, H.S. (2009)</b>  <i>"The impact of stroke consequences on spousal relationships from the perspective of the person with stroke"</i> Journal of clinical nursing Volume:18 Issue:12 Page:1803	Convenience sample, through letter of invitation <b>1.</b> Over 18 years, discharged from hospital following stroke diagnosis, living with a spouse, independent in ADL prior to stroke. <b>2.</b> Cognitive impairment, moderate to severe communication difficulties, dementia, terminal illness.  <b>SS=Stroke Survivor</b> <b>P=participant</b> <b>M=Male</b> <b>F=Female</b> <b>IV=Interview</b>	<b>1.</b> Rural Northern Ireland <b>2.</b> 16 Participants 33-78 years. 9M, 7F. Mean age 64. <b>3.</b> 2 months to four years. Mean lapse of time since stroke = 18 months.	Face to face IV's, in own homes. Audio taped IV and transcriptions coded. Provisional structure to IV. Relating to work role and relationships with spouse; i) Life before stroke, ii) life after stroke; iii) coping strategies adopted by participants when adapting to life changes. IV's audiotaped and transcribed. Average length of IV 25 mins. Handwritten notes after each IV.	<b>1.</b> Explore the impact of stroke consequences on spousal relationships from the SS's perspective. <b>2.</b> Systematic analysis using qualitative content analysis. Peer review for objectivity through academic supervisor. Emergent themes developed. <b>3.</b> Restricted to one health care trust. Sample size relatively small. Researcher known to the P's. In Northern Ireland cohabiting not the norm, which may affect the transferability of findings.	<u>1. the Dichotomies of pre and post stroke self</u> i) Anger proneness and irritability (unable to prevent outbursts) ii) Frustration, dependence, over-solicitous care and guilt).? <u>2. Sexuality, sexual functioning and desire</u> i) Sexuality, (now have a patient and carer relationship). ii) Physical appearance. iii) Sexual desire and sexual functioning (reduction). <u>3. Perceived loss of control</u> I ) Loss of role, identity and sense of self. ii) Socialising. iii) Fatigue. <u>4. Stroke a life changing event</u> Invisibility of less observable consequences of stroke and affect this has on relationships. Difficult to regain a sense of social control on a par with physical control. The effect

					of post stroke fatigue may have been underestimated. Better psychosocial support and training for those supporting stroke survivors is indicated.
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## Appendix C - Quality Appraisal of Key Papers. Based on Yardley (2000) and Spencer & Ritchie (2012)

Quality Markers	Bourland 2011	Burton 2000	Davidson 2008	Egbert 2006	Lynch 2008	Murray 2004	Northcott 2011	O'Connell 2001	Roman 2006	Secret 1999	Stone 2005	Thompson 2009
<b>Discussion of the implications of the research. Future research recommendations.</b>	Personal identity changes understood as a result of lost roles. Recommend intermittent long term intervention to aid adaptation over time. Useful to have quantitative measures of QOL to corroborate for LT trtm programmes.	Recovery is not linear, nor just physical. Social recovery vital. Currently a profssnl Rehab interpretation of recovery. Need new services to help SS and families to adapt to life after S. Needs a longer term focus in social context and SS exp important in this.	Shedding Light on everyday social communication. Programmes needed for assisting those helping SS with A.	SS Internal resources crucial regardless of disability	Need interventions with an Emphasis on acceptance and sense of belonging to increase positive outlook and determination. Need emphasis on relationship building to increase likelihood of community integration. Key Internal resources paramount; like communicate -on competence.	Expression of emotion for SS can be disabling. Post stroke counselling is needed for romantic and sexual relationships, and familial relationship and CG's.	Quality of pre stroke friendship important. Maintenance of pre S friendships as likely to be due to SS internal resources as it is to external factors	Very broad overview describing Impact of SS dependency. Carer needs, mental illness, social isolation. SS Need ongoing support out in the community. Need for educative Discharge materials, process for re-entry into workforce resources for support groups, education for public. etc	Attempt to advance knowledge of the recovery process. Process vs outcome following S. Crucial to repair the relationship to pre stroke self. Helps with recognition and trtmnt of cases for unresolved grief.	Activity more important than deficit measurement. Implications discussed for nursing. Need to focus on what is important to the individual – not offer unhelpful help or “doing” help	Huge concern with the reactions and expectations of others; and comparing self to others. P's reluctant to put selves in position where might have difficulties, can be easily misunderstood.	Invisibility of effects of stroke and effects on relationships. Social control difficult. More psychosocial support and training needed.
<b>Explanation of Study design</b>	Phenomenological thematic analysis. Each P, 2 IV's. Diary.	Phenomenological Informal 1 hour IV's (av 35 mins). collected monthly for min 1 year.	Ethnographic. Aimed at S with A. Matched controls, Multiple data collection methods. Very thorough.	Grounded theory. RH stroke only. 1-2 hours IV SS. 1-2 hours IV CG. Not clear about why selected RH SS.	Qualitative data analysis. Open ended questions in focus group IV's. Included CG's.	IPA due to exploring life worlds of P's. 5 IV's and 5 email P's.	Thematic analysis. P's purposely chosen for a range. I'Vs with use of topic guide. Field notes.	Thematic analysis using data system. Convenience sample. Five focus group 60-90 min IV's. Not well explained	Retrospective Case research IV's + archival time stable records, time series graphic displays, direct interpretation & pattern analysis.	Existential phenomenological Figure/group; Purposive sampling. IV 1 -1.5 hours.	Narrative study. IV Provisional structure. 3 hour Open coding scheme. Computerised data analysis.	Systematic analysis using qualitative content. Convenience sampling through letter. Provisional structure 25 minute IV



<b>Reliability and bias checks</b>	Themes discussed & checked with P's. research team analysis.	Continual analysis. . Log journal kept.	Triangulation.	Continual coding and checking. Corroboration from CG.	None discussed	Discussion of internal coherence and presentation of the evidence. No other checks.	Senior researcher evaluated early and later.	Bias acknowledged but no bias or audit checks explained	An audit trail and Participants checked the manuscripts	Well explained. MDT research group, Bracketing, Showed P's thematic structure.	Poor, not really discussed. Mention of research assistant; researcher has had HS. Helpful if she would have discussed her position more fully	Not strong. Supervisor only.
<b>Discussion of study limitations</b>	Yes, more varied P's would have strengthened results. Personal subjects not explored. No A no severe Stroke. Bias as O.T.'s	Only 2 participants filled in diary, more P's would have strengthened results. Personal subjects not explore. No A no Severe stroke.	Yes. Not transferable.	Discussed small sample size (25) and recruitment from SS groups (more motivated).	Small group. Focus group's might be less likely to allow disagreement Generated hypotheses didn't test them.	None	Very thorough and thought through	Focus group could prevent self expression	Not discussed	Discussed how well they had addressed bias.	Small sample discussed.	Fair discussion
<b>Enabling SS to take part in the study</b>	Not discussed.	Not discussed	Using visual scales and gestures	Not discussed.	Not discussed severe A excluded. Caregivers might be enabling.	IV's at SS convenience. Emailing responses around set of provisional topics; so P's could spend time in their responses.	Supported communication provided.	Not discussed	Yes. Included CG's. Describes waiting for responses.	Did home visits. Commented that all had neurological deficits.	Home visit	Home visit.
<b>Inclusion or exclusion of SS with A</b>	Not specified.	No	Purposely	No.	Excluded those with severe A	Yes included some aphasic P's.	Purposely	Not discussed	Yes both cases	Yes those with A and with marked A	Not discussed	Not discussed

<b>SS Population range</b>	From word of mouth, SS support groups. 6 P's, 3F 3M 58 – 79 years.	6P's; 4F, 2M.52-81 years Min 12 months post stroke	Older people only.15 SS with A and 15 matched controls. Mean age 71.60 years.	Mean age 60 yrs. Time post S not described	Mean age 54.7 11.9 mean post stroke period	10 P's, the mean age of the s was 49 years. Averaging 9 years post stroke	Rang of P's deliberately sought.	Good age range 20 – 89. 40 P's.	2 cases 45M, 79M.	Good range 40 - 93 years 7M, 7F, 9mths to 23 years post stroke	Good age range 19- 57, 22F, 3- 34 years post stroke.	Good spread of age groups 33- 78 years. 16P's. 18 mths mean time post stroke
<b>Clarity of the Inclusion /exclusion criteria</b>	Fairly open. 2 years post stroke and be English speaking	Broad, no depression, evidence of cog impairment , or other significant medical history.	Clear inclusion and exclusion criteria. Also explanation of use of tool to ensure A diagnosis	minimal	Very sparse. Taking those “able to engage”	2 years post stroke, self selecting	Very open excepting RH stroke	Not discussed	Not covered.	Exclusion not specified. Needed P's to be willing and able to articulate experiences	Very clear. Only haemorrhagic S and only women.	Good inclusion criteria, Not clear about how excluded
<b>Reviewers comments</b>	Very well presented and thoughtful introduction to the paper. Authors really understand their perspective. However their thematic analysis seems very limited and overly activity focussed.	No explanation of how to assess /exclude SS with no cognitive problems. The themes are very broad and not really adding much that isn't already known.	This study was impressive. It was clear within all aspects of study structure, and produced well argued themes	Found this study too over inclusive in its themes. It didn't carry an analysis that would have added a greater contribution to our particular understanding of RH SS challenges. Disappointing .	Focus groups very hard for SS with A without deliberate communication support. Including CG does help to provide an emphasis on social relationships however.	A good study, themes well discussed and the discussion of the results pulled them together well.	I found this very thorough, informative and well structured	Described as an Exploratory study may explain the thinness. Fairly basic findings. Study very thin in terms of explanation or exploration of issues.	Interesting and creative gave good insights into the world of the SS and how their characteristics to adjust, attitudes and ability underpinned their ability to recover	Really well written paper, thoroughly explaining the process of the work. Originally the paper discussed being a nursing study; however, the focus remained on extracting the meaning of the experience for stroke survivors. Very good diagrams for the structure of the theme loss and effort and the other themes.	Easy to read, well written. Advantage of different nationalities – good for contextual comparison women's perspective very interesting in terms of being seen by others. Time was taken to give the P's time to express their views.	Stroke support nurse who knew her clients. May account for strength of themes given that the IV's were only 25mins. Good evidence from the text of their accounts however.

<b>Quality of themes identified</b>	Really quite narrow, totally activity focussed	Although a good spectrum of themes. I'm not sure this adds to what was already well documented.	Excellent themes with good evidence from P's to support them.	Many themes seemed to include all of the possible effects and possibly lacked focus .	Wide social and emotional range of themes and sub themes, reported more like a text book list of headings regarding impact of stroke.	A good range of thematic results; from the existential to the personal to the social. More direct quotes from P's. Good discussion of themes	Comprehensive themes .	Poor	Good. Believable from the case histories	Very good diagrammatic form useful. Helps address the complexity of the subject area.	Feministic analysis with a specific type of stroke. Thought provoking	Covers a spread of thematic categories. Well explained and evidenced
<b>Academic justification And purpose</b>	Extensive and long cover of the literature in the area of QOL as a construct. Within QOL HRQOL was further described. 2 theoretical models – 'the model of human occupation' and 'the shifting perspectives model' described with the literature.	Brief synopsis appeared to cover the subject area over 4 main papers.	Covered a good area of conceptual literature relating to A, language, friendship, social support, older people depression. Good rationale.	Started with coverage of the particular challenges for SS from RH S. More coverage about social support theory. These do not seem to be linked together in order to make sense of the researched population.	Evidence of literature relating to stroke survival, QOL, HRQOL, and insensitivity to SS. Lit relating to Social functioning being more important to SS. Good lead into main goal of research to develop a disease specific HRQOL measure for stroke.	This is short but does briefly cover stroke effects, psychological well being survivorship and how personal accounts are lacking. Leads well into describing the current study.	Good summation of the Literature relating to friend loss, depression, isolation, failure to resume activities, the nature of friendship networks, literature re loss of friends after S.	Literature on stroke prevalence, literature on functional recovery and social contact loss. Wanting to explore and describe impact on SS of physical and psychosocial needs in rural and regional settings.	This was very thin. References to learning to live after a chronic illness and finding new ways to do that.	Short section within the introduction covering lit on S prevalence, QOL, rehabilitation and functional outcomes. Research understanding person as a whole missing.	Excellent review covering QOL for younger SS, women's perspective geographic al location, adults who had a stroke as a child. Lit re view of invisible disabilities. And experience of having a stroke.	Literature references concerning - medically biased outcome tools, qualitative studies to demonstrate experience of SS Younger SS, family support and carer psychosocial difficulties.
<b>Key:</b> P= Participants. IV = Interviews LT=Long Term profssnl= professional S= stroke HRQOL= Health related quality of life CG = Caregivers S = Stroke Survivor A= Aphasia exp= experience QOL=Quality of life Trtmnt=treatment												

## Appendix D Themes and Sub Themes across the Papers (21 Themes); selected for review

Identified theme	Bourland	Burton	Davidson	Egbert	Lynch	Murray	Northcott	O'Connell	Roman	Secrest	Stone	Thompson
<b>LOSS / MAINTENANCE OF FRIENDSHIPS AND INTIMATE RELATIONSHIPS. Connection / disconnection with others. 8</b>			*	*	*	*	*			*	*	*
<b>LOSSES IN SOCIAL WORLD, ROLE; LEADING TO ISOLATION 7</b>		*		*		*	*	*	*			*
<b>SOCIAL PARTICIPATION, COMMUNITY INTEGRATION – CHANGES. Being part/not being part of community. Engaging/not engaging in activity with others. 7</b>	*	*	*	*	*	*					*	
<b>PRE AND POST STROKE SELF, CONTINUOUS/DISCONTINUOUS SELF. the dichotomy. Contrast of previous life. loss and grief. Disrupted embodiment and loss of self 6</b>		*				*		*	*	*		*
<b>EMOTIONAL RESPONSES OF SS. EMOTIONAL LABILITY /SENSITIVITY EMOTIONAL RECOVERY 5</b>		*		*		*	*	*				
<b>PRIMARY SOCIAL RELATIONSHIPS Critical, strained, IMPOSITION. RELATIONSHIPS ESSENTIAL</b>				*	*	*				*		

FOR FEEDBACK 4												
IN CONTROL / OUT OF CONTROL 4		*				*				*		*
INVISIBILITY / VISIBILITY OF DIFFERENCES SINCE STROKE 3						*					*	*
UNHELPFUL REACTIONS OF OTHERS TO SS; e.g. PHYSICAL DISABILITY, SPEECH, INVISIBLE DISABILITIES 3						*	*				*	
GENDER AND SEXUALITY AND APPEARANCE 3						*					*	**
EFFORT / FATIGUE /slowing 3		*								*		*
SPEECH AND LANGUAGE COMMUNICATION LOSS DOMAINS 2			*		*							
DEPENDENCE/INDEPENDENCE UNHELPFUL HELP 2					*					**		
COPING 2				*	*							
PHYSICAL ISSUES/RECOVERY2		*		*								
A LIFE AFTER STROKE 1								*				
SS ATTITUDE TO CHANGE 1									*			
DENYING DISABILITY 1											*	
CHALLENGE OF ACHIEVING DAILY LIVING SKILLS 1				*								
FINANCIAL CHALLENGES 1				*								
COGNITIVE PERCEPTUAL CHANGES 1				*								
TOTALS	1	7	3	10	6	10	4	4	3	6	6	7

## Appendix E: The 5 most frequent themes reported across the studies in the literature review.

<b>Main Theme across the 12 studies</b>	<b>Subthemes</b>
<p><b>First</b></p> <p><i>Loss &amp; Maintenance of friendships and intimate relationships. Connection/disconnection with others.</i></p>	<p>1i Relationships and communication ability/disability</p> <p>1ii Unhelpful responses from others</p> <p>1iii Concern about the reactions of others to disability</p> <p>1iv The quality of communication with friends</p> <p>1v Relational ability affected due to stroke location</p> <p>1vi Stroke survivors relationship with their families</p>
<p><b>Joint second</b></p> <p><i>Losses in social world, loss of role and isolation</i></p>	<p>2i “Stuck in a cage”</p> <p>2ii “Deciding” to withdraw</p> <p>2iii Importance of Role in society</p>
<p><b>Joint second</b></p> <p><i>Social participation/ community integration – changes. Being part, not being part of community. Engaging/ not engaging in activity with others.</i></p>	<p>3i Not engaging as before</p> <p>3ii Its too difficult they won’t understand, I’m an imposition</p> <p>3iii Socially acceptable management of the body</p>
<p><b>Fourth</b></p> <p><i>Pre and post stroke self. Continuous/discontinuous self; the dichotomy. Contrast of previous life. Loss and grief. Disrupted embodiment and loss of self</i></p>	<p>4i Unfamiliarity of new life</p> <p>4ii Stroke survival</p> <p>4iii Disrupted embodiment</p> <p>4iv Continuous/discontinuous self</p>
<p><b>Fifth</b></p> <p><i>Emotional responses of stroke survivors – emotional recovery.</i></p>	<p>5i Emotional Responses</p> <p>5ii Loss of emotional control</p>

## **Part 2**

### **Research Report**

**“The experience and expression of social cognition changes  
for stroke survivors”**

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## **Abstract**

Six self selected stroke survivors (ranging from 1-9 years post stroke) were interviewed in order to gain their views and experiences regarding their social cognition changes since their stroke. Open ended qualitative interviews were undertaken and recorded verbatim and then analysed using Interpretative Phenomenological Analysis. Three superordinate themes emerged from this analysis; my changed sense of self in relation to others; managing my social behaviour; and my altered states of feeling. Each of these superordinate themes contained a number of sub themes. Stroke survivors' self-understanding of these issues and the impact on relationships regarding these issues is discussed and recommendations are made.

## **Introduction**

### **i) The effects of Stroke**

Stroke directly affects 152,000 people in the UK alone and of those that survive is the largest cause of longer term and complex disability. More than half of all survivors are left dependent on others for everyday activities (UK national statistics on stroke December 2012). Eighty five per cent of strokes occur when an artery in the brain is blocked (ischaemic stroke) and fifteen per cent are caused by bleeding within the brain (haemorrhagic stroke). Stroke is a medical emergency and national campaigns (e.g. act FAST campaign 2009) have increased the incidence of faster identification of stroke, whilst concurrently timely 'clot busting' hospital treatment has become more available, leading to less measurable brain damage from artery blockage (Wardlow 2009). Contemporary NHS hospital-based stroke rehabilitation has focussed on early recovery of physical ability, speech and language and adaptation to everyday living skills. More obvious effects from stroke include: physical disability to the limbs, altered sensation, spasticity and pain. There are far less visible effects including; swallowing, dysarthria and aphasia, visual problems, poor bladder control, incontinence, emotionalism, altered mood states and depression. Language and communication difficulties can occur as frequently as in eighty eight per cent of strokes (O'Halloran, 2009) and over 50 per cent

struggle with fatigue (Annoni, 2008). Any and all of these post-stroke effects take their toll on the stroke survivor \*(SS) emotionally and socially. The National Stroke Strategy (2007) clearly states that longer term psychological adaptation to the effects of stroke for both survivors and carers is viewed as one of the main challenges in stroke recovery. Specific mention is made regarding depression and relationships.

*\*Stroke survivor abbreviated to SS throughout the text*

The psychological effects of coping with complex disability, rehabilitation and adjustment have led to specific government publications recommending resources for psychological interventions as an integral part of stroke care. SS feedback regarding very poor levels of psychological support in order to cope with stroke as a long term condition was part of a Care Quality Commission review in 2011. The NHS Improvement in Psychological Care after Stroke Report recommended psychological services as part of a step care model, clearly showing the cost benefit of including a psychologist as part of the multidisciplinary care team and recognising the importance of psychosocial factors in stroke recovery.

The range of effects that can occur following a stroke are wide reaching and involve a variety of physical and psychological health factors. How a stroke affects psychosocial abilities and quality of life is much more difficult to conceptualise than just physical ability and recovery.

## **ii) Social Cognition and Stroke**

Paul Eslinger (2002) developed a classification of social executive processes and social impairments that could occur after stroke (see appendix F). In 2008 the American Society of Neurorehabilitation worked on a wide ranging consensus in order to conceptualise functional cognition following stroke (Donovan 2008; appendix G).

Amongst the ten cognitive areas in their taxonomy were the social use of language, emotional function and executive function in addition to more straightforward language ability. These three areas included Eslinger's descriptions of particular challenges for the SS such as being able to understand social rules, understand and use social language appropriately, have awareness of one's own and others' emotions and be able to juggle that information when needing to address other kinds of problem solving tasks. All of these skills rely on the ability to communicate clearly to others and where language has been affected this is an obvious challenge in social engagement with others. In the brain injury literature more generally, however, those with predominantly right hemisphere injury have been shown to have different difficulties with communication. Patients with right hemisphere communication disorders show changes in the way they use language, not always picking up on unstated or additional information (for example, making inferences or the use of facial expression) and fail to apply previously learned rules of conversation (Borthwick, 2012).

### **iii) Social cognition**

The concept of social cognition was initially termed social intelligence and was first identified by Thorndike in 1920, who described it as an ability to understand and relate to people (Ruisel, 1992). Emotional intelligence arose as a later term having its roots in social intelligence (Goleman, 1996) and the terms can seem interchangeable.

Salovey and Mayer (2004) argued that emotional intelligence subsumes both inter- and intrapersonal intelligences, bringing together the social and emotional concepts. Their theoretical proposal indicates that emotional intelligence has five principal features: being aware of one's own emotions; being able to manage one's own emotions; being sensitive to the emotions of others; being able to respond to and negotiate with other

people emotionally; being able to use one's own emotions to motivate oneself. The concept of social cognition has come to be widely used across psychology and cognitive neuroscience. It is used to refer to various social abilities disrupted in autism, for example, theory of mind (Premack & Woodruff 1978); and social abilities disrupted by head injury, mental illness or developmental disorder, for example dysexecutive control (Shallice, 1982). In behavioural neuroscience the biological basis of social cognition has been investigated (Havet-Thomassin, 2006; Hoffman, 2008) by using neuropsychological and other testing procedures following brain injury, indicating that many social cognition issues arise from interruptions within the right prefrontal and right fronto-orbito cortex.

#### **iv) Studies on stroke survivors views on social cognition following stroke**

There are many stroke studies concerned with minimising stroke risk using medications such as aspirin and warfarin (Mant, 2007); and cholesterol reducing statins (Chen, 2003). Understanding about stroke risk factors have led to an emphasis on health and life style advice in stroke prevention (NHS choices 2012) and directly following stroke recovery. There have been national drives to use early functional measures to assess for stroke damage and the effectiveness of rehabilitation (Ring, 1997; McPherson, 1996). These studies tend to be quantitative in nature and help with decisions about early service provision and treatment protocols following stroke. In early stroke recovery it is the more obvious physical and functional abilities that are attended to so that the SS can be as independent as possible. Early physiotherapy and occupational therapy help the SS regain as much functional ability as possible which can then assist ability with activities of everyday living (Kwakkel, 2004; 1997). Difficult or uncharacteristic behaviour is better tolerated in early stroke recovery as each week more gains might be

made functionally. The SS and their families often have an “illness model’ regarding stroke so that they expect to get better as one normally would following a physical illness (Dowswell, 2000). Social cognition issues begin to arise over time as the ways of relating that were previously established no longer apply in the same way and confusion arises concerning why the SS behaves and relates differently. There are as a consequence many studies concerning carer stress from family members adapting to a different role whilst also feeling distressed about the number of changes in mood and relational ability that the SS may be experiencing (Low, 1999). Many SSs and their families that visit the rehab clinic tell of significant changes in marital dynamics and in previous roles that the SS cannot fulfil in the same way (Palmer, 2003). Problems with self-awareness or denial following stroke that affect rehabilitation and social ability are very challenging (Katz, 2002) which can make the task of discussing this issue a difficult one. It can also be difficult to separate the loss of relational and emotional skills from anxiety and depression due to the myriad of post-stroke challenges. Formal testing procedures are used to assess for executive functioning difficulties such as disinhibition, perseveration and problem solving ability (e.g. *BADS*; Wilson, 1997; *DKefs*; Ellis, 2001) and a deficit in these skills could easily affect relational skills, but these test procedures are very much task-based or concern verbal and visuospatial reasoning that may translate to much more subtle interpersonal skills. Some screens are available to help assess for social cognition difficulties (e.g. Bisiker, 2013) but these are currently being evaluated and may eventually prove very useful. Studies that have sought to seek SSs’ views on their social cognition issues following stroke have therefore, most often involved longer term SSs and these studies have been embedded within research interest groups where difficulties in social cognition would have an effect on particular areas of social functioning: (see appendix H).

1. The first group concerns social and emotional experiences and the impact of these on quality of life after stroke; experiences that stand out affecting quality of life (Secrest, 1999); social functioning ability and its effect on dimensions of quality of life (Lynch, 2008); and social participation and occupation and quality of life (Bourland, 2011).
2. This second group gather SS accounts with a focus on relationship and social context; disability in social context (Stone, 2005); real life friendship analysis in older people and older people after stroke (Davidson, 2008); theoretical development for social support and integration (Egbert, 2006); spousal relationships (Thompson, 2009); and friendship analysis, perception of friendship and loss and protection (Northcott, 2011).
3. One study of two SSs' accounts together with a case analysis (Roman, 2006).
4. And fourthly, studies that ask the participants to recount their experiences after stroke more generally; living with the experience of recovery from stroke (Burton, 2000); exploring experiences of SSs after stroke (Murray, 2004) and experiences of strengths and weaknesses in the community after stroke (O'Connell, 2001).

Five of these studies explicitly include SSs with aphasia. The published research at the time of this study investigating how SSs view their personal social cognition changes after stroke is quite small and only just begins to describe how SSs view this very vital area of stroke rehabilitation.

## **Aims**

The aim of this research therefore was to further investigate SSs' views. Not just about their experiences as SSs but about their more specific experiences concerning their social cognition abilities and challenges. The author was interested in how aware SSs

are about this issue in their lives, and how SSs manage social cognition differences, in order to investigate more about this little understood area of experience. These experiences are common in right hemisphere stroke, but may not be confined to this group.

## **Methodology**

### **Design**

A qualitative research design was employed based on unstructured interviews. Six self-selected SSs, whose stroke had occurred at least one year previously, were invited to interview in order to talk about their experiences of social cognition difficulties since their stroke. The interviews were all audio recorded and then their accounts were transcribed verbatim. The transcribed accounts were then anonymised and analysed using \*Interpretative Phenomenological Analysis (IPA).

IPA was selected as the method to analyse the transcripts because ‘Phenomenology’ concerns those experiences which register as significant for the participant; those experiences which become important and are then recounted as “an experience”. IPA is concerned with the phenomenology of “deliberate controlled reflection” on the participant’s own experiences. IPA recognises a double hermeneutic (theory of interpretation) process with the participants engaged in “sense making” about their particular experiences and the researcher engaged in “sense making” of the participants’ accounts. IPA research can utilize small purposefully and carefully selected examples of participants’ accounts in order to illuminate detail and depth to allow for analysis and understandings between participants.



## **Ethics**

Ethical approval was successfully gained through a Regional Ethics Committee and supported by NHS Research Managers within two NHS trusts (appendix I)

## **Participants**

### **Inclusion and exclusion criteria:**

SSs were included: who had experienced a stroke a minimum of one year ago, were English speaking, and identified social and emotional interpersonal changes as a significant factor in their recovery. In order to participate, SSs needed to be able to attend comfortably for about an hour and be able to describe personal experiences relating to social cognition. SSs were also included who fitted the criteria above but for comfort, language or concentration reasons would rather communicate by email.

SSs were excluded if they had: diagnosed or borderline multi infarct dementia, receptive language disability, expressive language disability, significant comorbid health conditions that impacted on their experience of stroke recovery, or were non English speaking.

### **Recruitment**

Participants were recruited through the local Community Rehabilitation Team, the local hospital rehabilitation unit, and the Stroke Association. The researcher gave presentations about the proposed research to the local clinicians, local services and to the Stroke Association family support workers. Eight SSs expressed interest. One of these became unavailable due to family pressures, one eventually declined to participate giving no reason, so 6 were finally interviewed (see appendix J). Four of the interviews

*\*Interpretive Phenomenological Analysis abbreviated as IPA throughout the text*

took place in the participants' own homes and two within a community rehab facility. Five of the interviews were solely with the SS and one took place with the participant's wife also contributing. Five of the interviewees were male and ranged in age from 48 to 69. The one female was in her 40s. Five were white Caucasian in ethnic origin and one was Asian. Time since stroke was 1 year, 2 years, 8 years and 9 years. The mean age was 6 years, the mode 8 years.

All participants were given a participant information and invitation sheet (appendix K) before taking part that gave an explanation of what social cognition means following stroke and outlined the main purposes of the research. The same information sheet was then revisited before the interview as needed as some participants had made notes on the sheet and others used it as a reference throughout the interview. The information sheet was also distributed to stroke health professionals and to local SS support groups and networks.

The interviews were not structured and unfolded according to the interests of the participant. When the interviewer felt that the interview had drifted away from the topic, attention was then brought back to the subject of social cognition. Interviews took place at the location most suitable for the participant. Interviews lasted on average at just over an hour.

### **Recording of interviews**

The interviews were recorded using a digital voice recorder. These were then transcribed verbatim by the researcher. Interview scripts were then collated for analysis.

## **Position statement**

Due to the author's own position a number of epistemological assumptions were made. The author's relationship with SSs has been based on working as a professional Clinical Neuropsychologist in the field of stroke recovery for 10 years, mainly in acute and early rehabilitation. A Neuropsychologist is required to be frequently engaged with assessing for the deficits incurred after stroke in order to make recommendations and facilitate processes within stroke rehabilitation. The choice of research topic came from a lack of information about social cognition issues in stroke recovery, or any established way of assessing it, and a desire to promote discourses about challenges in social relationships for stroke SSs within the stroke community. Clinical experience indicated that many SSs had social cognition problems following stroke but that it was hard to engage clients concerning this subject. The author's philosophical standpoint concurs with "the ethics of care" (Held, 2006) sometimes known as "relational ethics" (Ellis, 2007). The main philosophical standpoint of "ethics of care" is the understanding that individuals and groups participate in a dynamic and on-going construction of themselves through their relationships with others. It is the care involved in these relationships which is crucial in creating a shared understanding of perceived social reality and allows for growth, nurturance and safety. The author clinically utilizes a relational perspective in her work based on attachment theory, with an understanding of the psychosocial and neuro-biological basis of attachment patterns; and how these are brought into play following physical health and brain injury trauma.

## **Procedure**

### **Analysis**

A qualitative, phenomenological approach was decided upon because this research is highly exploratory in nature, seeking to derive personal meaning from participants, whilst allowing for the complexity of personal experience (Silverman, 2005). IPA was chosen because of its emphasis on “*an individual’s personal perception or account*” (Smith, 2003, p.51) and “*participants’ personal lived experience and how participants make sense of that personal experience*” (Smith, 2004 p.40). In addition, the IPA approach is a dynamic two-stage process in which participants attempt to give meaning to their experience and the researcher attempts to understand the participant’s meaning; combining “*an empathic hermeneutics with a questioning hermeneutics*” (Smith, 2003, p.51).

### **Data analysis**

Transcripts of the interviews were read several times in accordance with Smith’s IPA methodology (Smith, 2003), using the right margin to begin to annotate interesting material from the data and the left to annotate emerging themes. IPA methodology was followed to complete this process for all interview transcripts. An initial analysis resulted in a number of emergent themes (appendix N) which were then examined and refined further in a more focussed pursuance of themes concerning social cognition effects. The themes were arrived at by the process of abstraction (Smith, Flowers & Larkin, 2009) whereby patterns were identified between initial emergent themes and grouped together under a more ‘higher order’ theme. The final stage of the process involved looking for salient patterns across all participants; (appendix M) enabling identification of recurrent themes specifically related to social cognition across all cases and arrival at three super-ordinate themes, (see table 1).

## **Validation**

Validation was carried out by:

- i) Discussions with a peer support group regarding emergent themes and their evidence.
- ii) Independent analysis from a clinical psychologist experienced in research of emergent themes from two of the scripts.

Research Supervision also enhanced validity of interpretations made. The function of the validity checks and supervision was not to perform an inter-rater reliability check as this is incongruent with IPA, but instead to develop and strengthen the coherence of the interpretation made by the researcher (Smith, Flowers & Larkin, 2009) *“To ensure that the account produced is a credible one, not that it is the only credible one”* (Smith, Flowers & Larkin, 2009, p.183).

Due to time constraints it wasn't possible to get feedback from participants regarding the thematic analysis. The results of the study however will be shared with participants. Participant comments will then be shared when disseminating this research to the Stroke Association and will be incorporated if the study is accepted for publication.

## **Results**

Three superordinate themes relating to social cognition difficulties following stroke resulted from the IPA analysis. These comprised a number of subthemes, and these are outlined below.

<b>TABLE 1: EXPERIENCE OF SOCIAL COGNITION ISSUES AFTER STROKE</b> <b>SUPERORDINATE THEMES AND SUBTHEMES</b>	
<b>1. MY CHANGED SENSE OF SELF IN RELATION TO OTHERS</b>	i) Mismatch of evolving survivorship and expectations at the workplace  ii) Role shifts - Being vulnerable and needing others to care – being more aware of attitudes of others  iii) The importance of how I come across to others - how important others view me  iv) Relationships are different now and that affects me  v) I'm a better person with more understanding/feeling for others
<b>2. MANAGING MY SOCIAL BEHAVIOUR</b>	i) Tactics to manage my social behaviour  ii) The Gatekeeper that's been thoroughly thumped  iii) Being on high behavioural alert-gaining control of a new part of me  iv) Being part of a conversation
<b>3. MY ALTERED STATES OF FEELING</b>	i) Increased emotionality  ii) I don't have that emotion anymore  iii) Being in this bubble

### Exploration of the Themes

#### 1. My changed sense of self in relation to others

This first theme '*My changed sense of self in relation to others*' described the role of the 'other' in relation to the self and the importance of this in the world of the SS. This was a very strong theme capturing how other people responded to the participants following their stroke and was described by all of those interviewed. The participants

described something fundamentally important about their feelings of self-worth, social/self-confidence, behaviour and capability through their relationship with others. Reactions of others could significantly help or hurt the SS's perceptions of their ability and social standing.

These accounts spoke of the challenges of reintegration into former social networks such as the workplace, as well as those that they now needed to negotiate. Abilities in negotiating with others had changed and the SS was not always sure how to evaluate the changes. Forming a post stroke identity with the help of the reaction of others in order to have mutually satisfactory relationships took time; within each set of personal interactions and in the acquisition of more self-understanding over time. Trying to reflect and understand differences in ability, adaptation and thereby identity since the stroke was described as an experience rooted in social interactions. These social interactions were a source of important feedback but could also highlight confusion and loss of certainty. Other people were needed to acknowledge value, difference and recognition of effort but others were not always able to do so because they might equally be unsure of how to react. The importance that the participants ascribed to important others for feedback in order to learn to survive their stroke in the best way they could was something that was also felt as a loss when previously relationships were experienced as more egalitarian. Two of the participants reported that due to their struggles they had a much greater feeling of empathy for others. Four of the six felt that they were better people and one did a lot of work to help others who were also SSs.

Xavinder was the most recent SS in this study. His stroke had occurred a year ago. He described how the stroke had affected his identity within his family so that he no longer knew how to be with them. He described how this left him feeling anxious so that he tried to avoid family situations.

*“X- [ ] Maybe they will be looking at me differently. Erm.*

*R- They’ll have a different view about you?*

*X- Yeah. Er*

*R- Do you think you’re different? Than you used to be?*

*X- Well I’ve had an event obviously..... and I am different yes I am” (Xavinder 482-486)*

i) Mismatch of evolving survivorship and expectations at the workplace

In the workplace, Xavinder and Barry described having had enormously hurtful experiences due to how people at work had dealt with them. As SSs many improvements were being achieved during rehabilitation but their previous work skills were not yet sufficient for those improvements to be acknowledged in the workplace. Employers seemed unable to understand or acknowledge the effects of their stroke(s) so that realistic return to work goals could be set. Xavinder and Barry describe their experience of return to work as a focus on their limitations rather than on their growing achievements.

*“..... I mean my confidence was knocked from the beginning you know just I was never really encouraged to do anything erm or encouraged in any way. Everything was so negative – ‘oh you’ve had a stroke so that means you can’t do this, you can’t do that [ ], that’s what I think wasn’t good for my confidence. .... I agree with some of it, I couldn’t do some things, but from the time I’ve had the stroke up until now there’s a lot of improvement.....” (Xavinder 442 – 448)*

Barry described attitudes at work as far more negative:-

*“...everything that went wrong, or everything that wasn’t done in a particular way was vilified, which undermined any progress that was being made” (Barry 165 – 167)*



From their experiences their workplaces displayed a general lack of understanding about the complexity of stroke recovery. At the same time their own understanding was growing about how long “getting better” was likely to take; highlighting the differences between what was being expected from others and themselves compared with their actual capabilities at any one time.

John, as the only participant who was currently working, described struggling at work because his stroke had left him with memory difficulties so that he needed a bit of extra support. The workplace wasn’t focussing on what he couldn’t do, but John was trying to tell them about his cognitive difficulties. Ultimately he was not able to gain help and support so that he would be able to work more efficiently.

*“... we do this training and I say, well look have you got anything in hard copy? I said because I can sit there and follow it, because you’re telling me, I’m grasping it now but it will be gone. By the time I get back two days later on the computer its gone because I can’t retain it” (John 624-627)*

ii) Role shifts; being vulnerable and needing others to care – being more aware of attitudes/behaviour of others

Part of the survivorship story concerned a closer attention to the attitudes of others due to a need to adapt to a different social role. Tony described more fully how his stroke had sharpened his ability to notice how others behaved around him because he now depended on them. Being in a role with less personal power, especially when needing care, led to a need to be more vigilant about how others were.

*“I used to feel stronger about those (nurses) that didn’t come over as the friendly caring sort than I perhaps would have done and I think this is my fault. I think that’s because I felt and still do feel so vulnerable, not able to deal with it or cope with it too*

*well myself, whereas in the past I could have just got up and said 'oh well I'm off' – I wasn't in a position to do that, I was so reliant that's what I mean by vulnerable. I was so reliant on these people I wanted them to be friendly and caring, I needed them to be. Cos I've got no way out myself."* (Tony111-117)

iii) The importance of how I come across to others - how important others view me

All of the participants talked about the struggle to negotiate opinions important others had of them since their stroke. Participants knew they were different to before and some expressed awareness that their relational skills were different.

Tony described how his wife complained that he was sharp with her when he hadn't realised that he was being sharp. He described how difficult it is because he cannot easily track how he might be coming over. Processing information concerning her overall attitude; processing what she says; and then responding, took such a long time. He is relationally capable he says, but his slowness in order to be capable gave him a feeling of incapability.

*"I don't remember being sharp with her, (wife) I think maybe now even now even?;[ ] not particularly capable to do everything and anything, that feeling inside. Not being able to cope too well, not because I'm not very able anymore to do things. First of all I can't work things out quick enough, I can work things out given time. I'm so slow at times and I feel as though erm I can't cope with that because I got to take it in due course, nice and easy."* (Tony 277 – 296)

John was concerned that due to his fatigue people would view him as lazy:-

*“.....and you know but some people perceive as being lazy and that’s what I find difficult. They perceive it as being lazy because they don’t understand you know; [ ], if you can’t see it, it doesn’t exist. They perceive it as being lazy. Well you’re alright this morning ‘yeah that’s took it out of me lifting all them boxes this morning you know. I can’t physically do it this afternoon you know it’s impossible’. It’s that understanding.*

*R – Then it seems like you understand that they don’t understand*

*J – Well yeah cos it seems like they’re not educated but I’ve tried to educate people that are close to me [ ] ... I was with my Dad it took ages, but then I was in the pub one day having a bit of a drink and he said ‘oh how you getting on’ and I said ‘I’ve just got to stay here now’. And he said ‘yeah he still gets a bit tired at times’ so I thought it’s actually gone in” (John 595- 608)*

This concern about not being sure about how others will view them could also then lead to an avoidance of social situations. Struggling in these situations was due to feeling like a ‘different person’ and not always knowing how to be with that difference.

iv) Relationships are different now and that affects me

All participants described changes in their relationships with family and the struggles that occurred. This ranged from Vicky’s need to keep as independent as possible and struggling with not allowing her husband to do things for her, to David’s acknowledgement of his lost holidays with his wife. Not being as capable and endeavouring to take up a similar role to that prior to stroke was hard to adapt to. Xavinder’s was the only interview where the partner was present. She contributed to the conversation as the interview went on in order to help clarify how the family had to

‘look out for him’ and how his role needed to change if only temporarily. He expressed the loss of himself in the role of her husband however.

X – *“so she’s been there for me and is ever so supportive of me but I think we’re not where we were a year ago....[ ]... – erm in many ways you know in common I used to confide in her and she used to confide in me, you know, and I don’t think she confides in me as much as she did then, erm*

R – *why is that then?*

X – *“I sort of think sometimes that she feels sorry for me erm I don’t know whether I feel that or she comes over like that [ ]before I would have been involved like everything would have been through me.” (Xavinder 304 – 316)*

Tony described moderating his behaviour in order to be as helpful as possible given the change in their relationships where his wife had to do so much: –

*“...I try not to be or say too much cos I know it will affect (his wife); it will upset her a bit being negative and worrying about things it will upset her. Upset is one word, get her down is another word. I try to keep quiet and don’t succeed well a lot of the time. I try to keep it to myself so it doesn’t get her down a bit try and keep her a bit more buoyant. Because I know that’s better if you can be like that. She’ll feel better, we’ll all feel better.” (Tony 485 – 490)*

Xavinder described being highly sociable prior to his stroke and strongly involved in the community. Now he was not at all sure how he was coming across to anybody which made him very uncertain about himself in his relationships.

*“...I’m not sure whether I’m right about certain things. If I say something and think about it. Was that the right thing to say? Or was that the right thing to do? And I’ve*

*felt you know many times its been the wrong thing and then that affects you and then you don't want to do it because then you think that might have been the wrong thing and that might upset somebody.” (Xavinder 505 – 509)*

v) I'm a better person with more feeling/understanding for others

Given that all participants found their post-stroke life challenging on so many levels it was interesting that most reported maintaining or increasing their feeling for others, and that this made them better people. They described being more civil, more understanding, being more constructive and being more empathetic toward others. An increase in empathy and understanding however could also be hard to deal with.

David described how he hadn't lost his empathic skills although he didn't regard empathy as a particular strength of his. He described during the interview that he had harshly judged a celebrity on the TV due to his prejudice. Sometime later, he had watched a programme about her life and came to understand the difficulties that she had to deal with and overcome. He had felt ashamed and described that his tendency to get obsessional and judgmental about others in this way had increased since his stroke, but his understanding of adversity had also increased, so that given more information he could see that he was being unreasonable. (David 186-283)

John described himself as a much more civil person now, trying to be more constructive in his dealings with others.

J –“.....and I say excuse me do you mind this or do you mind that and if they're defensive or thing against ya, it's that aggression will attract aggression type thing if you know. [     ] So. Do you mind you know. And say it politely and stuff you know.

..... and that, but I approach people better I think in a civiler way rather than give them chance if you like.

R – So some things have got better then?

J –yeah more constructive and things nnn yeah exactly. Well To be honest with you I think I'm a better person since my stroke definitely". (John 528 -547)

Barry talked about how much he valued achievement and when other people achieved things this really resonated with him. He described feeling *more* emotionally about the achievement of others which could be hard for him to manage.

"B -..... reading a book about somebody's achievement is very different because that brings on a whole series of memories associated with that achievement. Not necessary my memories but just I think erm putting myself into the place of that person and I can't get rid of that as easily.

R – What you're describing then is having more vivid empathy then.

B – Yeah Yes. I think that that probably is. I said that the strengths have been heightened and weaknesses have been...

R – So you feel it more

B – I feel more empathetic yeah.

R – Mmmmm And then that becomes tricky to deal with sometimes.

B – Mmmm. Mmmm". (Barry 333 - 345)

## 2. Managing my Social Behaviour

Participants described being aware of discrepancies in their social behaviour and how they tried to manage this. Awareness of social behaviour change was common to all the participants, although this awareness was not always consistent or reliable. This could be due to the SS's poorly controlled social behaviour, or to difficulties in responding to others due to cognitive or language processing problems. This awareness without necessarily being able to control their responses could lead to a great deal of anxiety and tension. Some of the participants described the great effort that went into self-management in order to be as socially appropriate as possible because it clearly mattered to them – as outlined in the first theme.

### i) Tactics to manage my social behaviour

John expressed concern that his behaviour could appear self-absorbed due to his processing problems and that he would come over to others as rude. In his account he speaks at great length about his difficulties in having reciprocal relationships when he finds language so hard to process and because he gets so fatigued. A major tactic he utilises is to apologise quite quickly.

*“.....I've been in a situation where I'm concentrating on something and something's happened somebody's said oo ooo sorry about that I've said and I've apologised ooo sorry because I wasn't thinking because I was so engrossed in concentrating on something that I may have appeared rude. Cos they may have said 'hello John' or something and I've said 'sorry' you know 'not responding straight away', or you know or somebody's opened the door for me and 'oh sorry, thanks' you know because I've been concentrating on something else that I hadn't had this 2 way thing. cos something was on my mind and I hate rudeness as well and things like that.”(John 286-294)*

David started the interview by asking me to help him manage his behaviour -

D – *“If I get too smart arsed Ruth just put me in my place won’t you Cos I tend to joke about everything, it’s my way of coping. You know almost if you take anything seriously at face value, you know I’m always looking to sort of, you know, make a joke out of things.*

R – *So you want me to say that to you do you?*

D – *erm no well I mean if I try to be too clever - yes please - you know, say. I’m aware that can happen, and I’m not a time waster (small laugh) so please, you know, just put me in my place quickly.”(David 1-9)*

ii) The gatekeeper that’s been thoroughly thumped

Barry described very well how early on in stroke recovery he had not been a good judge of social behaviour and how this can still be challenging for him:

*“.....erm I have never really been somebody to tell smutty jokes and sort of guffaw at them, but that happened and that upset my wife because that was something very different and my kids, [ ] were very very surprised at that. Erm Its one thing if you do it in private but when you do it in public. Erm My table manners were dreadful. I forgot all of my manners in terms of waiting. Toward the end of a meal if there was something nice left, I would just reach over and grab it if I wanted it rather than saying ‘Does anybody else want this?’ Of course my family were appalled at that.*

R – *So when you reached over and grabbed something then did you notice that they were finding that strange?*

B- *No –*

R – *You didn’t know?*



B – *Not initially er if I lapse now at any time I feel very embarrassed you know cos I know now that it is wrong erm and it's not something that I want to perpetuate".(Barry 81 -99)*

Barry described how he still had to be very vigilant about how he behaves with others. His way of explaining this to help him make sense of this behaviour has been in terms of the youth of his 'new brain' that needs to grow and understand.

R- *"So you still might lapse sometimes*

B- *Sometimes yes, yeah – again if I am very tired. And that's when my new brain isn't coping quite as well.*

R- *They are like social rules aren't they?*

B- *Yeah, yeah all the social rules and norms which I was very good at conforming with, and was noted for.*

R – *So is that like a monitoring, a self-monitoring thing? That isn't quite as good?*

B- *Yeah I suppose it's the gate keeper that's been er thoroughly thumped and isn't quite as good at doing what he used to do. – mm hmm." (Barry 100 – 106, 90 - 92)*

Barry clearly described his social behaviour as no longer automatic. How he monitors how he behaves now is much more of a deliberate conscious process than before the stroke. Just like David who asks me to help him monitor himself and Xavinder who is unsure about how he comes over, getting feedback from a trustworthy source is vital for learning and self-esteem; and may need to go on for some years.

*".....I was told off, by my family. yeah. And particularly my 3 lads who are stroppy teenagers and er they wanted their old Dad back erm. They still have difficulty with the*

*physical side of it but they acknowledge now the cognitive and psychological erm profile is back to nearly where it was.....[ ].....*

R – *So did that go on for a long time?*

B- *I would say it went on for the first, certainly for the first 3 years if not the first 5 years post stroke”. (Barry118 -127)*

iii) Being on Behavioural high alert – gaining control of a new part of me

Not having an automatic social monitoring system was described by Barry as then leading to the necessity to be on a high alert about how to behave acceptably with others when this is important to the SS. His account describes just how much conscious control he had to apply to himself and how he had to rationalise with himself about his behaviour and thoughts in order to do this.

B “- *erm I think because as I became more self-aware erm and erm was more on guard, in a social context erm whether it be family or friends or new colleagues; I’m on high alert to ensure that I give a good account of myself and don’t let myself down with those trivial things that - are important in our social interactions and they do make huge statements about who you are and what you are and it’s something that I’ve always taken notice of and I mind about them, so if I mind about them why shouldn’t other people mind about them if they see them in you.” (Barry 108 – 115).*

Although John described obsessive thoughts and behaviour that he considered unacceptable and his guilt about this, Barry’s account was exceptionally honest about how terrifying his unacceptable thoughts and behaviour was for him.

Barry’s way of coming to terms with what was happening was to attribute lack of knowledge to his new post-stroke brain. This “new” brain was developmentally much

younger than himself and didn't always understand how some things were not personally or socially acceptable. He described that he has had to work really hard to bring his new brain – the brain that has re-networked since his stroke - under control. Early on he described very vivid hallucinations and sexual fantasies which terrified him as they were totally out of character.

*“.....I suppose I rationalised it by saying, well look you've got a new brain there's parts of the brain now that doesn't know itself anymore it doesn't know the body, and it's trying to learn all those things again.[ ] So that's the way I sort of justified it to myself. In order to try and make it reasonable behaviour. It was horrible really, really horrible”. (Barry 585 – 590)*

Barry described how important social behaviour is to him and coming to terms with the loss of that ability. It brought into question who the “real” Barry was.

*”I think what was frightening was thinking is this part of me that's always been there and has been repressed – ...[ ] ... that frightened me, is this the real me that's been hidden for all these years and has suddenly been let out.....[ ] ....I count myself as lucky that there was that level of control that I could bring to there on anything that I thought needed controlling” (Barry 656 – 667)*

#### iv) Being part of a conversation – the challenge

All of the participants made some comment about the social challenge of taking part in conversations. Language is taken for granted as a way to be with and communicate with others and conversational ability can be challenging after stroke.

*“..... I can cope with lots of people now and I can cope with lots of conversations. It's very common post stroke to have a difficulty dealing with multiple conversations.*

*And [referring to earlier in his recovery] I'd pick up on bits of conversation and internalise them and hold them and then suddenly at a totally inappropriate time I'd come out with some pearl of wisdom ( laughs) that was five minutes too late.....[ ].....and they'd gone on and I didn't understand.....[ ]..why people were upset with me. Sometimes people did get very upset. My wife got very upset with family conversations and couldn't understand why I couldn't keep it in and it was just something that sort of had to come out.”(Barry 450 – 462)*

Withdrawal from speaking up was also described as an option because conversational engagement could be so difficult

*“I would rather just sit there quietly than attempt to enter a conversation lest I couldn't carry on with it properly because I couldn't hear it or hear it clearly or process what was being said very well” (Tony 212 -214)*

*“.....sometimes you see I just - don't bother saying it. You know I think oh well I won't bother saying my piece now because it's gone. What I wanted to say is not ..... at the time now and I forceful and some of the words had gone and you'd got really good wording so when you did come out and say it; it jumbled up”. (John 108 – 111)*

John described lots of tactics that he had for dealing with conversations, but it was still hard work for him because he found keeping up so challenging.

*“Yeah because I've tried to manage it. To an extent I've tried to; (sharp intake of breath) there is no set pattern as to what to do. I've tried to listen a bit and stay calm, control and then remember what you wanted to say and try and come out with it. And*

*wait for your moment rather than think I must get in there quicker otherwise I'll lose it.*

*Yeah so I'm trying to .....*

R – ..... *That's another cognitive skill as well then isn't it, to actually supervise yourself.*

J– *Yeah, and in the meantime; not lose the thread of what the other persons saying.*

*You know if they've made a point and then go onto make another point erm which could actually be backing up what they've said and you come in and say ooo what about ... ooo you know. So it looks like your criticising and not listening.*

R – *You're very aware of how complex that all is.*

J – *Yeah definitely yeah"* (John 141 – 152)

### **3. My altered states of feeling**

This theme did not include those emotional feelings that were described throughout the interviews such as loss, terror, fear, depression and hope, which would be expected to occur after any significant life event or illness and is well reported in the stroke literature (Hackett 2005, Western 2007). Rather, this theme focussed on participants' accounts of particular states of feeling that were persistent and could occur almost as a separate experience to other kinds of mood that would have been more recognisable from pre-stroke experiences. These were identified as experiences when physical arousal structures (body sensation/behaviour) connected to emotion were different since the stroke and/or their ability to evaluate or monitor this experience was also different (Mandler, 1984). All were able to be reflexive about their emotional reactions and experiences, although this awareness did not necessarily occur until some time had passed since the stroke event. Specific emotional states since stroke ranged from

increases in lability and feeling more intensely emotional to the opposite extreme of not experiencing feeling. The ‘not feeling’ was either described in terms of absence of feeling or as a kind of numbness. Successful management of these emotional states relied on the SS having some cognisance of the state approaching which was not always possible. Managing their own anxiety and managing social situations with a different and unreliable set of emotional responses continued to be challenging. These particular experiences within SSs were also described as occurring largely within relationships and could lead to interpersonal strain.

i) Managing Increased emotionality

Responding more emotionally is something that five of the six participants described as a significant issue for them. Some used the term lability. Barry had already described that he was already an emotionally sensitive person prior to the stroke and felt that the stroke had emphasised this part of him. The challenge for Barry and the others was to be able to manage emotionality in social situations.

*“.....I was always quite an emotional person anyway, so it wasn’t something that traumatised me. It upset others erm and confused my family because although they knew that when I was upset I would show it in the form of tears erm when I was suddenly getting tearful at ridiculous things they were totally confused and that upset me.....” (Barry 238 -243)*

Barry described how he took steps to manage his emotional times in order to avoid upsetting others; he feared losing emotional control in social situations; describing being “raw” if novel things took his feelings by surprise.

*B- “for my closest friends, close family they’ve experienced it so much now – they still comment on it, and to avoid them being distressed I will just hide myself away and I’ll opt out.*

*R – So you know it’s coming?*

*B- Yep*

*R – And then you remove yourself?*

*B - Yep*

*R- And then just wait?*

*B – Yeah and you know it’s a negative strategy that I don’t like, but it’s the one that I think is the kindest.*

*R – For how long might you have to wait?*

*B- 10 minutes to 30 minutes perhaps - if it’s a really bad one.*

*R – Okay so there’s degrees as well*

*B- Yeah yeah”, (Barry 315 – 328)*

ii) I don’t have that emotion anymore

Vicky described her emotional lability, but then also went onto describe having lost some emotional feeling that she used to have. She described different things mattering now, but couldn’t articulate what the lost feeling was.

*“I do have quite strong lability. Where I – I might be telling T (her son) off for doing something one minute and then I go into laughter. Erm and then I can go from laughter to tears very easily. I mean we were always before the stroke watching a film or*

*hearing a song, erm both of us can be quite teary it brings back memories and things but there's other things where a film might have meant a lot to the 2 of us and now I don't have that emotion anymore. I have noticed that"* (Vicky 119 – 124).

It can be difficult to locate the loss of a feeling in the light of so much emotional lability that may not reflect real feeling. I noted that during our interview Vicky was the participant who found it hardest to describe her own or others' feelings; even though she was extremely articulate.

ii) Being in this bubble

This was Tony's description of not feeling alert and clear headed in the way he did before his stroke. Whilst some of this affect could be attributable to shock and adjustment, there seems to be a process that occurs (often called fatigue) leading to a lack of clarity in thinking, which is frequently described by SSs due to the physical impact of the stroke itself. Being 'in this bubble,' as Tony described it, made reaching out and interacting with others more difficult; as when he was in it he found it hard to pay attention to much outside of himself. Although he was better it is a feeling state that he still experienced.

*".....I suppose growing out of it is something that's just happened that I haven't noticed. I am really appreciative of having grown out of that most of the time. Some of the time I still feel a bit that way. Most of the time I feel a lot more erm 'with it' to use the phrase now and able to have a conversation with someone and detect as you say a some of the things you mention here; some of the things that you say in here, some of the things that you talk about. Facial expressions, tone, sarcasm all that sort of stuff. I think I can detect that now pretty good. I don't remember other than the fact that I was*



*totally vacant not being able to detect it before. I don't think I could. All I remember is being in this bubble". (Tony 36 – 44)*

## **Discussion of results**

Eslinger's (2002) descriptions of the challenges in stroke rehabilitation; understanding social rules, using social language, being aware of one's own and others' emotions and juggling this, are seen very clearly through the descriptions of the participants in this study. Issues like trying to manage conversation in social communication, having to deal with relationships being different and feeling different, dealing with increased emotionality and self-control were all themes already well represented in the literature. Within this study more specific exploration about social cognition yielded a much more private and rich understanding about SSs' struggle with social interactions and emotional management. What was striking was just how much participants reported struggling with these issues, largely privately, whilst a self-understanding evolved over a very long time. SSs spoke of constantly having to reassess how they were coping and what it was that wasn't working so well. Their social relationships, caring for loved ones and having to be cared for mattered a great deal to them and this was stressful when monitoring themselves within those relationships could be so hard to do.

### **Self in relation to others**

The overarching major theme from this study concerned SSs' sense of self in relation to others, and this also highlighted the discomfort in relationships because of the adjustment and confusion for SSs within their social and family group. How others reacted was seen as important. In this study, 'not feeling understood' was not generally expressed, with the exception of attitudes within the workplace. A great dislocation was expressed about expectations in the workplace and the pace of stroke

recovery and this echoes the work of Northcott (2011); especially for younger survivors.

Participants also described painful rejection from the work place which Aleszewski et al, (2007) also explored in their review of SS experiences return to work. SSs reported how successful return to work needed more and longer rehabilitation, better liaison between professionals and employers and more recognition of complex and hidden impairments such as fatigue and cognitive problems. Without these facilitating factors realistic return to work planning was unlikely.

With the exception of return to work, this study told us more about the positive efforts that SSs made to deal with the discrepancies in what might be expected from them and their social performance and how important it was to them even when they chose to withdraw socially as a management strategy.

This could be understood as a loss of self and personhood which was reported in Murray's work (2004) when SSs described not being the same person and having a continued estrangement from the person they were. This estrangement was not a particular focus in this present study. This may have been due to the interview style of asking participants about process rather than just feeling, so that more emerged about how things were dealt with in relational terms. The other factor was that those that participated had come in response to a study about social cognition – although it was the author's impression that only two, Barry and John, had given this issue a lot of thought prior to being asked to participate

As other studies showed, the very people (family and friends) who highlighted changes in social manners and reacted to changes in “normal” behaviour, were also helping to bridge the schism of the discontinuity in the SSs' lives (Secrest, 1999). Secrest

identified the underpinning ground themes as 'loss' and 'effort' and this could easily be applied to the social cognition themes that emerged from this study. Participants expressed their relational loss in terms of their social cognition ability and then described the effort that they made to be able to work with that.

The struggle of needing to be cared for and feeling vulnerable in that relationship is also expanded upon. As Held (2006) discusses in her work on Ethics of Care, in western culture we strive to be seen as individuals and believe that we have a separate identity to others, but we are only able to feel that way because of the support and care in our relations with others, particularly when we need care at different points of our lives. Increases in support and care which need to occur after a stroke affect the SS's view of self particularly when recovery takes such a long time.

Particular to this study was the sub theme about being more aware of the attitudes of others because of having a more subordinate role and needing to be more aware of those that the SS depended upon. Participants described being aware that they were in a different power balance with others. The descriptions of more awareness of the attitudes of others may reflect this difference in relational 'power'. Having less status can lead to more observance of 'the other' (Snodgrass, 1992) as this has been shown to increase interpersonal sensitivity. The place of others in the SSs' lives in this study was understood by them as crucial. I was struck by the general level of self-awareness expressed by participants even at times when their internal experience was terrifying. Participants described themselves much less like victims of decreased abilities but as having to acquire and accomplish more agency over themselves by adopting strategies despite the frustration and bewilderment that could occur. The reality may have been that social communication skills were worse than before and participants weren't that good at compensating but their awareness that they needed to be active in managing this

was particular to this study. This even went as far as asking me to help manage behaviour that might not be acceptable; so not to waste my time. As Blum (1994) asserts “concern for others is not separable from concern for self”.

Participants described the importance of how others see them. The literature describes the difficult paradox of having an invisible problem and not wishing to be seen as disabled or less valued (e.g. Stone 2005), while simultaneously needing others to understand that SSs were different and had invisible disabilities. Social representation theory (Duveen & Lloyd 1986) utilises a conceptual framework for understanding the renegotiation of identity that occurs through reciprocal processes of relating others to self, and self to others, in order to build up a stock of social representations that would now fit an altered identity.

Participants acknowledged the impact that they had on their carers, in their new relationship. Acknowledgement of vulnerability may well lead to a better negotiated relationship. When one person can actually claim vulnerability, this allows the other to meet the need and so a relation of trust can be established (Kittay 1999). That would appear to be what Tony was describing in relation to his wife.

The final subtheme within the first section concerned being a better person and having more feeling for others. This concurs with recovery from other types of life changing trauma in the literature. Post traumatic growth following head injury has been seen to ultimately increase skills in “relating to others, personal strength, thinking of new possibilities, appreciation of life and spirituality and this appeared to increase over time” (Powell, 2007). McGrath (2006) also reported increased empathy and understanding for others. To the author’s knowledge this phenomenon has not yet been widely reported in the stroke literature.

## **Social behaviour**

Tactics to manage social behaviour clearly showed evidence of engaging problem solving strategies reliant on effective executive (frontal lobe) functioning ability. Disrupted abilities to monitor, inhibit and self-regulate are generally attributed to lesions or disrupted networks occurring within the orbitofrontal cortex (Rolls, 1996). Much of this literature however concerns brain lesions after traumatic brain injury (TBI). What has been described in this study might be better understood anatomically through the work of Carrera (2006) when he discusses the behavioural syndromes that can occur following infarcts that can interrupt the four main arterial thalamic territories. During Barry's account it can be seen that re-engagement of these systems after his stroke took resolve and determination. Barry's description of his 'new brain' was rather like the birth of an ego state that had emerged separately and which challenged his conscious executive control, bringing all the chaos of a mental health problem. This may have begun as part of an acute confusional state following stroke (Gustafson 1993) leading to psychotic experiences. Very little has been reported about psychotic experiences following stroke. Almeida (2007) discusses psychosis as one of the mental health difficulties that can occur following stroke but what is mostly reported throughout the literature is depression and anxiety in longer term stroke survivorship. Barry's description of his terrifying experiences and how this evolved might be better understood through a Kleinian framework such as Rosenfeld (1965) where he discusses how serious confusional states arise when the normal mental structuring between 'good' and 'bad' breaks down so that a person's experience has no structure.

Emotional regulation (Teasdale, 1999) requires an on-going attentional and recognition ability of emotional state which is crucially dependent on the presence and conscious

experience of the person. Barry is describing an interruption in that process which he learns to 'regrow' and adapt to by deliberately being alert to this deficiency in himself.

### **Altered states of feeling**

The effects of increased emotionality following stroke has been well documented throughout the stroke literature (e.g. Thompson, 2009). SSs (e.g. Newell, 2010; McCrum, 2008) have described the perplexing phenomena of and the difficulty in controlling emotional responses. Lambie and Marcel (2002) describe the importance of having emotions as the emotional experience gives meaning to the way things are or the way things were. The emotional experience following stroke can be a much more intense physiological and hedonic event. In this study the issue concerning emotionality was in respect of how increases in emotionality affected social and relational ability. The descriptions about intensity and appropriateness were to do with the effect that this had on others and in turn affected relationships.

Alongside increases in emotionality was also the reporting of increased empathy and the difficulty of managing this, given that increases in feeling could be hard to manage. Increased empathy was variously described as feeling more acutely (being more raw) to being more aware of the predicament and struggle of others.

Having a lack of an emotion and not being able to identify what it is that is now missing after brain injury has been attributed to the effect of ventromedial prefrontal impairment (Bechara, 2000). Lambie (2002) describes the phenomenology of an experience (a first order of lived emotional experience) as being more like an immersed experience where one is likely to be more immersed in a feeling of something being just as it is. Perhaps the over immersion as described in over emotionality could be described as more of a phenomenological experience. A second order experience is

more reflexive and is more concerned with knowing about an experience. He describes how the self (as a spatial object) and the (outside) world are always in some particular kind of spatial and relational consciousness. This can be disrupted following brain damage which affects the right hemisphere (Klonoff, 1990) and this may well be what Vicky was describing.

As parietotemporal regions are proposed to be involved in processing emotional information and in mediating autonomic arousal, and frontal regions are involved in emotional valence, perhaps the interaction of these two underlying neural systems were no longer able to communicate efficiently as before. Vicky could describe emotional lability whilst also describing a feeling of the lack of an emotion that was no longer there.

Although Tony did not describe his bubble as being the result of fatigue, this may have been what he was describing. Belmont (2009), in a study of people with TBI and fatigue, asked participants who reported significant fatigue about their subjective experience of how able they were, whilst also measuring their abilities. These findings suggest that patients whose injuries resulted in more severe attention deficits had to produce higher levels of mental effort to manage a complex task, which appeared to increase subjective fatigue, in line with 'the coping hypothesis' (Van Zomeren, 1985).

### **Limitations**

The participants in this study all had strokes that involved the right hemisphere and in the literature this is more likely to lead to communication and social comprehension difficulties, not directly related to language (Lamberti, 1998). Participants however reported that their social cognition skills were reasonable and that they had understanding of their difficulties with social cognition issues and had adopted varying

management strategies. There have been studies however which suggest that SSs with right hemisphere strokes and their partners do not always make similar assessments. Visser-Keizer (2002) found that while left hemisphere SSs agreed with their partners on the number and severity of most changes, partners of right hemisphere SSs reported more frequent and more severe changes than the SSs themselves. The observable altered behaviour, distress of the partner, together with hemispatial neglect of the right-sided SSs emerged as factors leading to the disagreement between SS and partner.

In this study, of the six participants, only one partner was present throughout the interview, and their accounts of the difficulties did not appear to be different.

Xavinder's wife had a different focus in encouraging him not to avoid others now that he was different. It is arguable however that without corroboration from significant others it is hard to know what the perception of important others about the participants' understanding and management of their social cognition issues were.

Respondent validation would certainly have given weight to the thematic analysis of the study and may have been a significant weakness.

This study was small, and this is usual for IPA studies. Caution needs to be taken regarding the results however as a small study whilst informative, may lack generalizability.

## **Implications**

The implications of this study are that those SSs who are struggling with the effects of social cognition issues have awareness of this because of the effect that their behaviour has on others. SSs learning how to evaluate their behaviour whilst at the same time learning about a new sense of self would appear to be something that is done largely



privately because of the time it takes to process all this information and because the understanding of self in relation to others is not a fundamentally linguistic process. Expecting SSs to be able to discuss these changes before they can process this into awareness would not appear to be helpful as an immediate strategy. However clear feedback with as much positivity as possible, in the spirit of understanding the cognitive affects of stroke are indicated, to promote self-esteem and prevent anxiety and depression from also complicating the recovery process.

### **Recommendations for future research**

Further research is recommended to make more sense of the SSs processing of their social cognition issues. Exploration of feeling might be better explored using non-linguistic media in order to support the tracking of change within the SS's understanding of him/herself and others. A more compassionate view of how the SS is able to understand and make sense of social cognition changes inside and outside of him/herself would be useful and aid in more appropriate therapeutic approaches to this vitally important area of stroke recovery.

## **Summary**

This study has shown us more about what is happening in the mind of the SS when relationships are difficult, and about their internal struggles regarding their social and emotional abilities. Three main themes emerged. The main overarching theme was “my changed sense of self in relation to others” with related themes of “managing my social behaviour”; and “my altered states of feeling”. These accounts and the themes that have emerged add to the evidence base about personal views of the challenges following stroke survival in the very important area of social and emotional relationships.

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## Appendix F

### EMPATHY AND SOCIAL-EMOTIONAL FACTORS IN RECOVERY FROM STROKE

Paul J Eslinger, Kari Parkinson and Simone G. Shamay

Current Opinion in Neurology 2002, 15:91-97, 2002 Lippincott Williams & Wilkins 1350-7540

#### Classification of Social Executive Processes and Social Impairments after Cerebrovascular Damage

Social Executive Process	Clinical Manifestations
<b>Social Self-regulation</b>	
1. Initiate	Akinesia, mutism
2. Sustain	Disorganised
3. Inhibit	Impulsive remarks, actions
4. Shift	Rigidity, perseveration
<b>Social Self-Awareness</b>	
1. Self-knowledge	Denial of deficit
2. Self-monitoring	Inappropriate remarks/actions
3. Social schemes	Lack of anticipation and planning
<b>Social Sensitivity</b>	
1. Understanding others	Reduced empathy
2. Theory of mind	Self-centeredness
3. Emotional sharing	Insensitivity
<b>Social Discourse</b>	
1. Metaphor, humour	Literal communication
2. Theory of mind	Decreased complexity and understanding
3. Intonation	Increased 'listener burden'
<b>Social Salience</b>	
1. Arousal, intensity	La belle indifference
2. Meaningfulness	Loss of social roles and boundaries
3. Motivational significance	Low initiation in important activities

## Appendix G

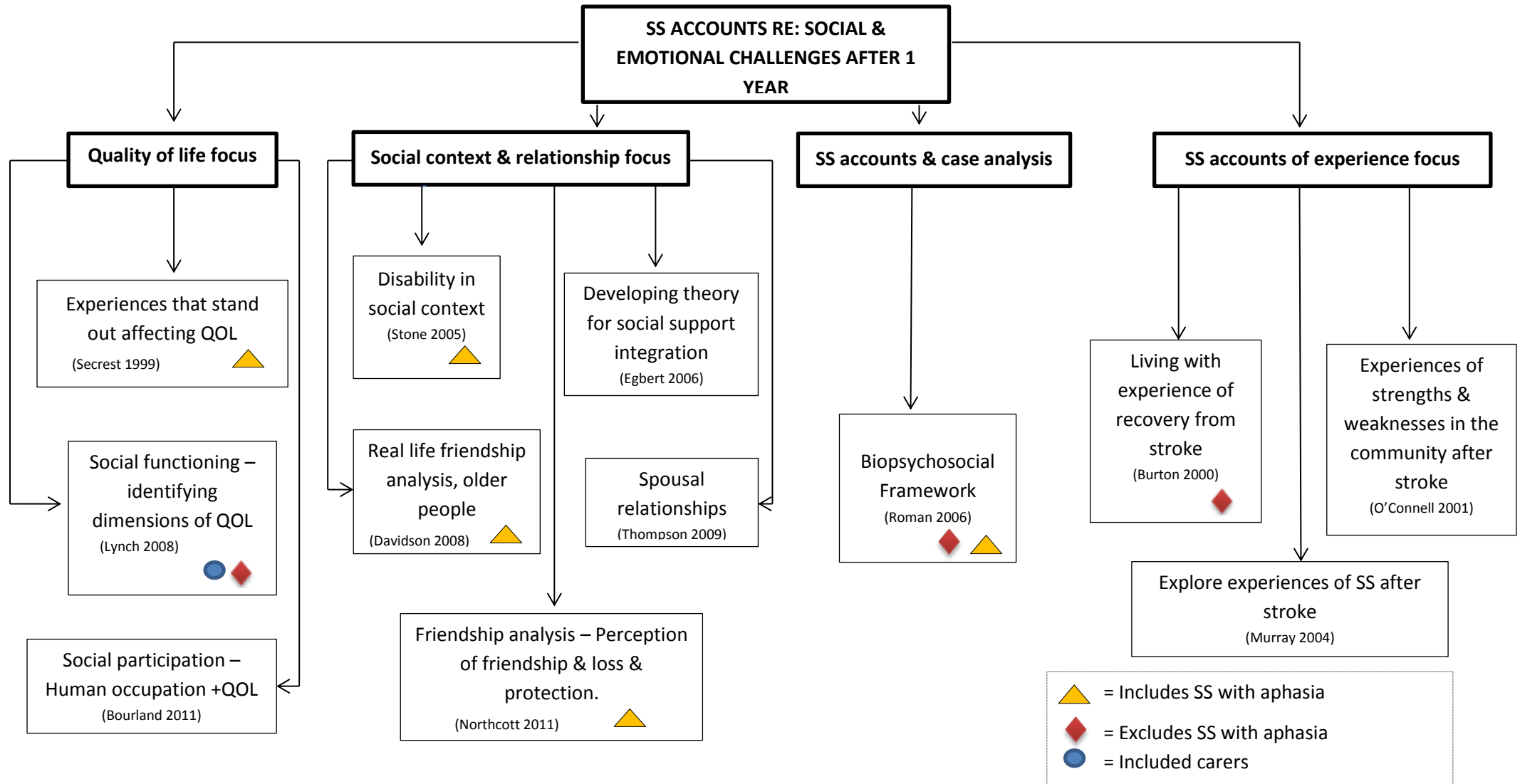
### CONCEPUALISING FUNCTIONAL COGNITION IN STROKE

Neila J. Donovan, PhD, Diane L. Kendall, PhD, Shelley C. Heaton, PhD, Sooyeon Kwon, PhD, Craig A. Velozo, PhD, and Pamela W. Duncan, PhD. Copyright 2008 The American Society of Neurorehabilitation  
Neurorehabilitation and Neural Repair 22(2); 2008

#### Final Domains of Functional Cognition and Their Operational Definitions

Final Domains of Function Cognition	Operational Definitions For Domain
Language	Ability to understand and/or produce spoken language.
Reading & Writing	Ability to read printed material and write words and numbers.
Numeric/Calculation	Ability to process numerical information and/or perform mathematical calculations
Limb Praxis	Ability to perform skilled purposeful limb movements in the presence of motor function.
Visuospatial Function	Ability to perceive and process visual information in one's environment.
Social Use of Language	Ability to use language to interact with others, including use of appropriate content, expression or comprehension of pitch, loudness or rate that conveys the speaker's emotional intent (prosody), management of a conversational topics (cohesion), and interplay between speakers (turn-taking).
Emotional Function	Awareness of emotional state of oneself and others and the ability to manage those emotions in terms of both personal emotional management and the management of emotions in interpersonal interactions. Also encompasses self-awareness of deficits and abilities (anosognosia) and the presence of emotional dysfunction (i.e. depression).
Attention	A variety of functions that include: selectivity, focusing, sustaining concentration or vigilance, switching, and modulating the intensity of attention.
Executive Function	The group of cognitive processes responsible for guiding, directing, and managing cognitive, emotional, and behavioural functions, during novel tasks such as organizing thoughts and activities, prioritising tasks, managing time effectively, and decision making.
Memory	The capacity to retain a variety of information, for varying durations, and use it for adaptive purposes.

## Appendix H - Literature Map



# Appendix I – Ethical Approval Letter

*Health Research Authority*

**NRES Committee North West - Cheshire**  
Research Ethics Office  
Barlow House  
3rd Floor  
4 Minshull Street  
Manchester  
M13DZ

Telephone: 0161 6257821

Facsimile: 0161 6257299

26 March 2012

Ms Ruth Telfer  
XXXXXXXXXXXX  
XXXXXXXXXXXX

Dear Ms Telfer

<b>Study title:</b>	<b>The experience and expression of social cognition changes for stroke survivors</b>
<b>REC reference:</b>	<b>12/NW/0145</b>
<b>Protocol number:</b>	<b>UNOLE 0264 version 1</b>

Thank you for your letter of 7 March 2012 responding to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved by the Chair.

## **Confirmation of ethical opinion**

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

However, please note that Information Sheet needs to be proof read for grammatical errors such as "i" should be 'I' and the word 'isnt' should read as 'isn't'.

## **Ethical review of research sites**

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

## **Conditions of the favourable opinion**

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior the start of the study at the site concerned.



*Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.*

*Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.*

*Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites {"participant identification centre"}, guidance should be sought from the R&D office on the information it requires to give permission for this activity.*

*For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.*

*Sponsors are not required to notify the Committee of approvals from host organisations.*

**It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).**

**You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. Confirmation should also be provided to host organisations together with relevant documentation.**

### **Approved documents**

The documents reviewed and approved by the Committee are:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering Letter		07 February 2012
Evidence of insurance or indemnity	University of Leicester - AON	16 August 2011
Investigator CV	Dr Ruth Telfer	
Letter from Sponsor	Email from Francesca Morgan - Research Governance Officer	
Other: CV - Dr Stephen Melliush		
Participant Consent Form	2	05 March 2012
Participant Information Sheet	2	05 March 2012
Protocol	1	06 February 2012
REC application	3.4	06 February 2012
Response to Request for Further Information		07 March 2012

### **Statement of compliance**

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

### **After ethical review**

#### Reporting requirements

The attached document "After ethical review - guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

#### Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website> After Review

12/NW/0145

**Please quote this number on all correspondence**

5.

With the Committee's best wishes for the success of this project

Yours sincerely

@  
~

Chair

Mr Jonathan Deans

Email: [Shehnaz.ishaq@northwest.nhs.uk](mailto:Shehnaz.ishaq@northwest.nhs.uk)

Enclosures: "After ethical review - guidance for researchers"

Copy to: Ms Carolyn Maloney  
Acting Research Governance and Development Manager  
College of Medicine  
Biological Sciences and Psychology  
University of Leicester  
Leicester  
LE1 7RH

Dr Kxxxxxxx,  
NHS Trust  
xxxxxxxxxxxx  
xxxxxxxxxxxx

Dr Steve Melliush  
Department of Clinical Psychology  
Leicester University  
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LE17LT

## Appendix J – Table of Participants in Study

Participants in the ‘experience and expression of social cognition for stroke survivors’ study

	<b>David</b>	<b>Barry</b>	<b>Vicky</b>	<b>Xavinder</b>	<b>Tony</b>	<b>John</b>
<b>Approx age</b>	69	Early 50’s	40’s	40’s	Late 60’s	48
<b>Gender</b>	Male	Male	Female	Male	Male	Male
<b>Time since stroke</b>	8 years	9 years	2 years 3 months	1 year	8 years	8 years
<b>Available information about stroke location</b>	Right hemisphere	Multiple strokes largely in the right hemisphere.	Right hemisphere/probably RMCA	Right hemisphere	Dense right hemisphere stroke	He was not sure but has left arm and leg weakness
<b>Work status</b>	Already retired	Retired due to stroke	Plans to return to work	Wishes to return to work – had to leave.	Already retired	Lost his business – now employed in part time work.
<b>Interview</b>	Own Home	Rehab Facility	Own Home	Own Home	Own Home	Rehab Facility

# **Appendix K - Research Participant Information & invitation document**

## **Invitation to consider being a participant in a research study-**

Invitation version number 2 Information version number2 March 5th 2012 RT

### **“The experience and expression of social cognition changes for stroke survivors”**

. . .

My name is Ruth Telfer and I am undertaking a research study about social and emotional (social cognition) difficulties that stroke survivors experience following stroke.

I have approached you with this information as you may feel that you have struggled with these issues since your stroke; and may still be dealing with them.

Before you decide I would like you to understand why the research is being done and what it would involve for you. I will go through this information sheet with you and answer any questions you may have. This may take 20 – 30 minutes but we can take as long as you need.

The first part of this information tells you about what the study is focussing on, and then goes on to describe the purpose of the study. This information then goes on to explain how the study will be conducted in more detail and how those that choose to participate will take part.

Please ask me if there is anything that is not clear.

#### **What is social cognition**

Social cognition skills are those which enable us to –

1. Be aware of how we feel inside and how we come across to others.
2. Successfully choose when and how to say things to others so that we can get along with others in different kinds of situations.

These are complex skills and are guided by our cultural experiences and learning.

When our social cognition works well, we get along in our relationships and in various social situations because we can “read” many of the subtle and non obvious meanings that happen during conversations and in social situations. We are able to “read between the lines” of what people say and not just take things at face value.

People use words in a certain tone or with a certain facial expression which effects the meaning that comes across. When our social cognition works properly we can make judgements about whether whats being said goes with the tone of voice or the facial expression. In that way we can make judgements about character and what to trust about what someone tells us, for example.

As part of how we communicate, someone might let us know how they feel in a way that isnt straight forward. Sarcasm, innuendo, or double entendre are examples of someone saying one thing when really meaning something else.

Another important social cognition skill is being able to imagine how another person might think or feel about something. This makes us anticipate how another person might behave when hearing particular news or in a particular situation so we can anticipate how we will need to be with them. Approaches to other people can then be altered accordingly appreciating that they have a different world view. The skill of empathy is included as part of this as this gives us “the feel for” others and the understanding of how their circumstances might effect them.

### **How is this relevant to stroke survivorship?**

Studies that focus on people recovering from brain injury have shown that when damage occurs in the right side (hemisphere) of the brain, or when the frontal lobes at the front of the brain have been affected, problems with social cognition can occur.

The frontal parts of our brains are responsible for processing lots of complex information. Understanding and weighing up all the elements of social cognition is complicated.

The right hemisphere of the brain deals a lot more with the processing of feeling which is also a vital skill in social cognition.

Information that is written about recovery from stroke does not describe the struggle that stroke survivors have with social cognition very well. Terms like depression and personality change get used a lot.

Understanding more about how stroke can cause loss of these vital social and relational skills; and what this is like to experience will help us to understand more about these issues after a stroke.

This research will also inform those who help stroke survivors and their families so that we can have more specific and constructive conversations about this challenging area in stroke recovery.

### **About this study**

This study is the main submission for a Doctorate in Applied Clinical Psychology and is being undertaken by myself as a Clinical Neuropsychologist with 10 years experience of working with stroke survivors. My intension is to expand awareness and dialogue about this emotionally stressful area of stroke survivorship.

### **What is the purpose of the this study?**

This study aims to find out more about social cognition difficulties from stroke survivors themselves when they feel that these issues have been (or still are) significant in their stroke recovery.

### **Method of the study**

The method is qualitative. I will approach stroke survivors either -

- A) because they have been through Rehabilitation services or
  - B) because they have identified themselves as dealing with these issues, through Stroke Association networking;
- and who are at least one year on from their initial stroke event. I am expecting that those who identify social cognition issues in recovery will have had a right hemisphere stroke and/or a stroke that has affected their right frontal brain areas. I will be inviting those stroke survivors who wish to participate – to tell their story whilst this is digitally recorded onto an audio tape. Afterward the interview will then be transcribed verbatim and then this will be analysed using a technique called interpretative phenomenological analysis (IPA). This analytic technique pulls out the themes of the different participants so that they can then be put together as evidence of shared experience. All the transcripts will be anonymised and pseudonyms will be used in describing the text.

This will then be written up for the qualification and presented at the national stroke forum and other stroke related events if requested.

### **Why have I been invited?**

This information has been given to you because, either a rehab worker has identified this issue as something that may have affected you in your stroke recovery or because you have spoken about this issue amongst other stroke survivors via the stroke association or related forums.

### **Do I have to take part?**

Its up to you to decide to join the study. I will describe the study and go through this information sheet with you. If you agree to take part I will ask you to sign a consent form. You are free to withdraw at any time, without giving a reason. This would not affect any other aspect of your stroke care.

### **What will happen if I take part?**

If you agree to take part, then I will discuss with you the best venue for the interview to take place. This may be your home or another place that is convenient for you. I would be expecting the interview to last about 1 hour but the length will be up to you and what you feel most comfortable with. Whilst a face to face interview might be best, other similar studies have used email correspondence when those who wished to participate felt more comfortable with this.

### **What are the possible benefits of taking part?**

There are no direct benefits to yourself if you take part, although many of us gain benefit from telling our story and having this heard. Your contribution may also help other stroke survivors as the study will be shared with the stroke community.

### **What will happen if I become distressed?**

Talking about how a stroke has affected your emotions and relationships can lead to feeling emotional and distressed to some degree. If this happens I will check with you how you are in order to make sure that you are able to deal with how you feel.

In the event that you feel highly emotional and you tell me that this is too hard for you then I will work out with you how to get immediate support to assist you so that you can manage how you are feeling.

If following on from our interview it becomes apparent that you cannot manage how you feel then I will both discuss with you how to get immediate support and assist in getting more professional support either from stroke services, community health or mental health services in collaboration with you and those that know and care for you.

### **What happens when the study stops?**

The transcriptions will be kept securely for 2 years following the end of the study and then they will be destroyed.

### **What if there is a problem**

If you have any concern or complaint about this study you should speak to the researcher in the first instance. I will do my best to address your concerns or address issues that are important to you. If you remain unhappy and wish to complain formally then you can contact the University of Leicester Dept of Clinical Psychology with whom this research is registered .

### **Indemnity**

In the event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action or compensation against Leicester University, but you may have to pay your legal costs. The normal NHS complaints mechanisms will still be available to you (if appropriate).

### **Confidentiality**

All ethical and legal practice will be followed and all information about you will be handled in confidence. All information about the participants in the study will be changed so that anonymity will be maintained and pseudonyms will be used when needing to quote from the verbatim spoken word.

As the study also takes into account the type of stroke sustained, the researcher may look at the CT or MRI records in order to clarify this information if you do not know about your stroke location.

No other associated research projects will have access to any person identifiable information.

No information about your contribution to the study will be disclosed to your GP or any other health professional without your specific consent unless you are expressing ideas that would involve harm to yourself or to others.

All research in the NHS is reviewed by an independent group of people called a research ethics committee – this study has been reviewed and given approval by the NRES Committee North West Cheshire.



# Appendix L – Consent Form

## Consent Form

Centre Number:..... Study Number:.....

Title of project:

“The Experience and Expression of Social Cognition Changes for Stroke Survivors”

1. I confirm that I have read and understood the information sheet dated ..... (version.2) for the above study. I have had an opportunity to consider the information, ask questions and have had these answered satisfactorily.

Please

initial.....

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason , without my medical care or legal rights being affected.

Please

initial.....

3. I understand that CT or MRI information about the nature of my stroke may be looked at by the researcher and i give permission for her to have access to those records.

Please

initial.....

4. I agree to take part in the above study.

Please

initial.....

Name of stroke

survivor.....date.....signature.....

Name of person taking consent

.....date.....signature.....

When completed: 1 for participant; 1 for researcher file.

## Appendix M - Researcher conducting the Thematic Analysis



## Appendix N Initial Analysis – IPA Recurrent Themes

Initial Analysis - Experience and expression of social cognition for stroke survivors IPA Recurrent Themes							
Sub Themes	David	Barry	Vicky	Xavinder	Tony	John	% theme presenting
<b>Super ordinate Theme 1 Relational issues</b>							
Stroke has strengthened Family bonds	*	More about adaption	*	More about brokenness	*	mention about Dad understanding fatigue	50%
Stroke has affected Family relationships	*	*	*	*	*	*	100%
Dependency, Independency and vulnerability in family	** Takes up sick role	X	** Importance of independence over small domestic things	** Wanting, needing and rejecting support	** Reliant, not doing my fair share	X	67%
Being let down/not understood by - friends/other important social groups - isolation	* abandoned	* Destruction of relationships	* Sister	* Work place, family Professional incompetence	X	* Taken a long time for friends to understand	83%

Importance of how others respond to me. The manner of others. How others view me	* Relationship with stroke survivor and loss of friends	* Vital for FB and learning	*	* Who said what? Affects are invisible to all. Effected by lack of understanding	* How wife is treated affects me	* Others not understanding auditory memory problems	100%
Wanting to improve things for other SS's	*	* Educating public, using experience as a tool in world	* Active in helping other SS	Always had been involved in helping others	* Wanting the IV to help others	* Helps others, wants me to help others	83%
<b>Theme 2. Tangible changes and losses from the stroke affecting emotional and social relationships</b>							
Cognitive disabilities affecting functioning	*	*	*	*	*	*	100%
Language disabilities affecting functioning	X	*	X	X	X more a problem of slowness	*	33%
Physical disabilities affecting functioning	*	*	*	*	*	*	100%
Fatigue as a significant factor in all kinds of social and emotional ways	X but he does not leave house	*	*	X	*	**	67%
work Loss	X Already retired	*	* although believes she will return	*	X already retired	* Lost his business though now has work	67%
<b>Theme 3. Emotional states since stroke</b>							
Emotionality / emotional lability post	* More emotional	*** Understood as regulation	* Lack of talking emotions.	X	*	* Lack of control. More empathy	83%

stroke		problem. 'Not normal'. More empathy	Emotional responses are different –but can't think of examples				
Existential fear / terror		** Total terror Loss of me		** Of getting things wrong Lost			33%
Depression/suicide	*					*	33%
Anger and frustration	* Expressed more against himself	* Used to do better	* Used to get on	* A lot of the text	* Due to slowness	* Greater awareness of aggression	100%
<b>Theme 4. Stated Attitude and ways of Coping</b>							
Using humour	* Although not always sure if appropriate		*		** Dry humour		50%
Identification of self as strong / resourceful	X	* Self control Using skills. Keeping occupied and distraction. Strengths stronger weaknesses weaker.	* Finding out, getting funding. "adaptation" Viewing self as lucky. Strong will.	* Always had good skills	* Daily routine, pace.	* Has character strength, self belief. Got educated	83%
<b>Theme 5. Social Behaviour - adapting behaviour to different social situations</b>							
Managing to make judgements about how to behave with others ,	* Not sure if he will be	*** Family had to act as	X	* Losing track of ideas – fear of	* Struggle when not enough time. Can be	* Importance of not appearing rude.	83%

including politeness, manners	inappropriate in IV	gatekeepers, until he could		saying “wrong thing”	sharp		
Difficulty managing conversations with a cognitive/language delay	X	* Impulsive verbal contributions	* Recognition of diffics due to communication diffics. Rapid speech	*	* Don’t talk to others to manage	* Managing interjections – losing words. Inappropriate timing. “Butting in” Rapid speech	83%
<b>Theme 6. Relationship with self</b>							
What is normal? What is normal post stroke?	* Sees himself as extraordinary.	*were unacceptable parts of personality part of me, or the stroke?	* Focus on aiming for normality	* How was I normal before?	* Not sure what normal is anyway. I have a sense of what is normal for me now.	* Normalising what to expect . Learning what my normal is.	100%
Personal history, Growing – development of self.	* This may be self inflicted for my past behaviour. I find myself interesting. Constantly reviewing past.	* End of life, past life, new life. The new post stroke person, merging. choices	* More me as time goes on. Focus on the way she always was. Getting back	* Stroke made me into different person. Never be the same again. A not person. Having to reinvent self.	* Its not as good as I wanted it to be. Hard to know what causes what. So much is aging.	* I am a better person. I have to live constantly managing myself. I use my energy more usefully. Time for my own pace.	100%
<u>Key</u> X subtheme does not occur *Theme occurs in this participants account ** Increase in asterisks indicates that theme occurs very strongly in this participants account							

## **Part 3**

### **Reflective Critique**

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## **Reflective critique of the work**

### **Choice of research topic.**

The idea about this research topic had been with me for a long time. The arena of social cognition and how it was affecting stroke survivors in the longer term was a clinical conundrum that was familiar to me. When I saw SSs and their families clinically it was usually in the context of how the SS was difficult to deal with because of self absorbed or unthoughtful behaviours that left their partners/carers bewildered, alone and angry. This was not necessarily the SSs agenda and so conversations were hard.

I had discussed the issue with SSs and workers and had presented current ideas at local plenaries but the topic didn't seem to inspire that much debate and I still felt very stuck about how this was experienced by the SS. Did SSs understand that these skills were different? Was this really like the kind of deficit present for people with aspergic difficulties?

I struggled with how I could assist SSs and their families when this difficulty arose as there were no real discourses about this other than 'personality changes'.

### **Choice of methodology**

I recognise now that I did have my own preconceived views that SSs probably wouldn't have much insight into social cognition discrepancies and difficulties because so much of what I was involved in clinically was how to help with this kind of deficit when family relationships had broken down. It was already known that SSs struggled with these issues especially those with right hemisphere strokes.

In my clinical toolbox, I didn't even have a checklist that I could go through to identify problems that was user friendly, that would help nudge SSs and their families and carers into sharing these issues.

In general I felt that in SS forums it was too easy to see the whole set of issues as the SS being in a depressed mood and unable or unwilling to acknowledge behaviour that could get out of hand.

I originally conceived of using a battery of tests in order to test for social cognition difficulties. I had thought of using face and emotional expression tasks similar to those used by Simon Baron Cohen and a film used to assess difficulties in social perception that had been used on a number of mental health and autistic spectrum populations. It seemed however that this wouldn't necessarily help me clinically, or expand the constructs for the SS community regarding this topic. I felt that a research method was needed that could enhance the development of conversations with SSs in order to help them and their families to work on such issues.

The best way forward then was to ask SSs themselves about what they thought about social cognition issues, how in their experience this had occurred and how this had evolved over time – or not.

In my search about how to take the research methodology forward, I became aware of Interpretative Phenomenological Analysis, which I felt was a real breath of fresh air. So IPA was selected as the best approach for investigating direct personal experience. It meant that I was able to directly lift from the verbatim accounts those elements of social cognition challenges that SSs reported occurring and attempt to synthesise these experiences over some different accounts. I speculated that I would also have to think about social cognition aspects within the interview itself, as an hour long interpersonal

encounter would highlight such processes. I found the prospect of working in this way both exciting and rather scary.

I was encouraged not to go in to this endeavour with an interview structure, or even a semi structure, which is what I originally produced. I was worried that without a structure SSs wouldn't be able to stay on track and that merely talking with me would not be enough for this process to unfold.

I was also used to 'getting things done' and making good use of time so that I would usually have conversations where I was the one in control, ending with goal setting or some other kind of plan, so to allow things to evolve was challenging for me.

### **Epistemological Stance**

In order to do a research study that hoped to be as facilitative as possible and in which I could declare my bias, I needed to think about where I was coming from. In truth it had been a long time since I had to think about this. At one time I would have called myself a socialist feminist or a social constructionist but things have moved on, and the role of third wave therapies and twenty first century ethics has begun. I then discovered the work of Virginia Held concerning relational ethics and this really encapsulated how our cultural ethics can be highly individualistic and non acknowledging of the care we all need from each other. Ethics of care attends to actual differences between persons and groups emphasising the importance of interdependence, relatedness and positive involvement in the lives of others. It explains how a culture of neglect for the real life issues occurring for us all, every day, can occur because of a lack of personal attention to community. From the ethics of care viewpoint, as we form our relations and communities – they are more than instrumental mechanisms for the satisfaction of

individual preferences; rather, they are extensions of empathetic relatedness between people.

Firstly, this helped me to ground my concerns about why social cognition is so important. Having these skills is not just about being able to ‘read’ and respond to others, but also concerns the importance of being able to be authentic and vulnerable with others as a normal part of human experience. The SS is a person in their individual context having to work through these issues in their communities.

Secondly, I could own that my own practice regarding this issue lacked the relational philosophy that ethics of care highlighted. I was far too mechanistic in my thinking, hoping that ways could be devised to assist with emotional skills that were deficient. I had not seriously considered that being ill or incapable socially could be viewed as part of life; within an ethics of care framework and that this understanding could be developed empathically within relationships.

Thirdly, much of the emphasis on researching differences in social cognition from the carer’s perspective or examining brain damage deficits involved in social cognition processes was actually viewing a stroke survivor in isolation, when the need to be ‘cared for’ and ‘managed in society’ was viewed highly individualistically.

Ethics of care helped me to understand a value system I wished to aspire to as a clinician, and perhaps I sometimes do this, but I had certainly not approached the research initially in this way. Encapsulating that this was my philosophical approach did assist me in addressing my bias and certainly would have coloured participants’ accounts when they were with me. It is no accident that my themes have a strong relational bias.

## **Ethics and research governance**

I set about this thinking that applying to the ethics committee was going to be very straightforward. However, this was a process that took much longer than I anticipated. As the process went on I recognised that all the parts of the research had to match. Everything had to tally with everything else in respect of all the details. For example the amount of time after stroke for the inclusion criteria had to read the same on the protocol and the invitation and had to be consistent. This was harder than I thought because it is in doing the research protocol that all the thinking gets done. For example, why would the research participants need to have experienced their stroke at least a year ago? I really needed to be clear about why I had put this in.

Focussing on the detail of what would happen if someone got upset or distressed was also something I really had to think through, as this is what the committee wanted clarification about. This is such an obvious thing to me to take care of. I am used to being the person who deals with the distressed people while at work; the one who picks up the pieces, but how would I handle that in the role of researcher? How do the roles merge or separate when asking about very personal information?

I recognised when listening back to the interviews that I had asked questions and perhaps probed that bit further just because that has been a normal part of how I have functioned with stroke survivors; and because I get so very curious! The skill of judging just how far to probe and how far to support was a clinical skill that I just took for granted. I really wasn't sure where the clinician/researcher line was in that respect.

I could understand the ethics committee's concern to detail about care of the participant as asking people to comment on their abilities concerning social cognition might be challenging.

I did struggle with how to make the information for the participants reader-friendly especially to a group of research participants that might be more likely to struggle with lots of verbal information. I don't think I achieved that very well because I tried to be all-inclusive to get over the idea of what social cognition is. I think that a few of the participants just didn't read it because they couldn't.

### **Finding the participants who would take part in the research**

I had to rely on those who knew SSs, rehab workers, SSs and their networks. I hadn't realised how asking people to talk about such an intimate area of their recovery might not be that popular. It is after all, easier to focus on aspects of physical recovery and how that challenge is met, rather than focus on the more psychological. I also hadn't accounted for it being harder to handle upsetting things when talking to a researcher who is a stranger.

It actually wasn't like being a clinician when people come because they want to discuss their emotional recovery, or want assistance to find a way through their experiences.

Those that volunteered were people who wanted to talk about their recovery and how they had achieved this, and at the time of interviewing were able to talk about their resources. The other notable thing they all had in common was that they all wanted to give something to help other SSs, and that was a recurring theme. All those interviewed expressed a desire to help others like themselves which was an interesting thing given the research topic and was reflected in the thematic analysis.

### **Interviewing**

I was very aware of my role, endeavouring to be a research interviewer as opposed to clinician and holding back so as to not lead the participant into processing information.

I'm not sure I always did that - as mentioned above. I had dilemmas about stopping what I thought might be participant rambling, and encapsulating what had been said in order to promote processing and synthesis in the participant. I know I also slipped and found myself making links that I knew to be likely given my experience. I tried not to ask too many direct questions.

I did find the experience challenging. I had no idea whether I had done the task of interviewing well or not, I was trying to go with what came up and was also wanting to get the richest accounts from the participants and so my evaluation of my own performance fluctuated hugely. Partly I was struggling with my tendency to quickly formulate models for what the SS is telling me in order to get as full a picture as possible.

### **The interviews**

Every time I read them, including the time that I actually engaged in the interviews, they seemed different. Meaning is so interpretable and open to mood and exposure. I guess the more I read and re read and become immersed, the more my experience of them evolved until they became the themes that seemed apparent to me at the time of writing. It would have been so much better if those that participated were involved in discussing the themes. Also of course this may have been too much to ask from some of them.

### **Transcribing the data for the IPA**

This took a very long time. A week's typing in the first instance, getting all the information that was on the tapes onto the page and then another couple of weeks just going through this to make sure that it was all down properly. Fortunately I really

enjoy typing. The process put me more in touch with the linguistic style of the participants because I did endeavour to transcribe verbatim. This meant a lot of repetition and stilted text because of the language difficulties. It made me much more aware of linguistic style and how much this enables social interaction and ease of listening. This process made me much more aware of the kinds of difficulties that authors were describing about aphasia in the literature review.

As with a lot of the research, I did things more than once because I did them in a way that wasn't quite right the first, second or even the third time!

The whole issue of not having a peer group became more and more apparent as time went on. Simple things like, 'how do you create a set of text boxes that also have numbered lines?' became a challenge over 3 weeks as I sought to find out from whoever I could ask. I didn't know that in order to do this, special software would be needed.

So after a shaky start, because I hadn't put the transcriptions onto a table and couldn't work out line numbering, I finally got it together (without text boxes) and started to enjoy the process.

### **Doing the IPA thematic analysis**

Well I was really looking forward to this. Then when I started cutting out the bits of text and putting them together on jolly bits of coloured paper I began to have doubts. What were the themes? I had a good enough knowledge of the participants accounts to know that there were overlaps in their accounts and sometimes there were not, but I could not be sure that I was doing the right thing. And then I went and looked at another chapter about IPA and of course they did the analysis in a different way so it



didn't mirror mine. By the first half of putting the thematic analyses together I didn't feel at all confident about it!! When I came to show my supervisor the themes he wasn't very impressed. I had wanted to include all that was said so as to make sure that I had been true to the participants' accounts. What my supervisor said was that he would be able to see that in any text book! What I needed to do was really draw out the parts of the whole that related to social cognition. This needed a lot more concentration and thought. It was then that I realised that I needed to do the interpretative bit. I was involved in this, and that was part of the point of the IPA. This work was my interpretation. The conversation that had occurred, had occurred in relation to me and it was part of the 'deal' that I would acknowledge this in the way that I interpreted the accounts as a whole. In a way, this felt better. I needed to be as true as possible to the spirit of what participants told me, evidence this well and really try and take this subject area a bit further by fusing accounts.

I spent a lot of time on the write up, having bursts of tackling the scripts, and then leaving them for a while to allow for processing time. I really enjoyed coming to a place that I felt gave the greatest coherence to the material.

It's a very creative process and I enjoyed this part of the the PsyD the most. I hope that from reading the work it is clear that I did my best to maintain sensitivity to context, commitment and rigour and transparency and coherence throughout as Lucy Yardley recommends (cited in Smith Flowers & Larkin 2010). It was a disappointment to me that I did not include respondent validation in my study. Originally that was just because I had not considered this. Then when I came to think about it sometime later, when one of the participants offered to help, I just didn't have enough time to rewrite the protocol, go back to ethics, and contact the participants again. I was also aware that for some of them it would have been a big ask, whilst for others they would have really

been glad to have been involved. Allowing for participant feedback from those who felt able to give it would have really enhanced the research process and results.

For the future, and future dissemination of the work, it will be interesting when participants read it as I will be asking those that participated to comment and think about how to make use of the study with the Stroke Association.

### **What I learnt about SSs and social cognition**

In truth, I did not expect to hear the wealth of information concerning social cognition issues, awareness, struggles and ways of dealing with these that came from the interviews. It reminded me of when I first qualified - when at that time, 'voice hearer's' (as part of a national movement to assist those with psychotic experiences) were invited to talk about what went on for them during those experiences. 'Professionals' had always discouraged such conversations because it might make 'schizophrenics' worse or encourage delusions. Psychologists and other health professionals have been actively involved with these groups since that time; exploring a voice hearers relationship with their voices has been at the heart of learning to live with them more harmoniously.

I think I was just as stuck in my ideas about how some SSs did not appear to have very much social cognition awareness and that it would not be particularly helpful to explore this with them. I had read all about how much brain damage can alter these abilities, and my bias had arisen from having spent a lot of time with early SSs when these issues were at their height.

In my defence, for those SSs and their families returning some time later for psychological help, relations had broken down considerably and the SS was by that

time, viewed with anger, annoyance, or sheer frustration. It generally did not occur to me that under the exterior of passivity, many SSs would be paddling away furiously trying to manage their social faux pas, language manners, impulsivity, lability and sexuality *because they cared about how their behaviour affected their family and relationship* but that it was just too difficult to even begin to grapple with or explain.

Relationships for SSs can become just so fraught, when it looks like the SS does not care about how they behave with others, especially significant others.

The study really helped me to understand how important an area this is for SSs. Those who are able to articulate the impact of their social cognition issues and how they deal with this – are so helpful for other SSs.

### **The literature review.**

I did find the literature review to be the most tortuous part of the research process. I just didn't understand the systematic bit. Conceptually it passed me by for about a year. I didn't understand that I needed to trawl the research that kind of covered the area, and it was in the invention of the trawl that the literature search was created.

I also initially didn't record the search strategy, and then later didn't record the exclusion process, and for this reason ended up doing the whole exercise 3 times. I came to realise the painful truth that having a secretary, assistants and a librarian on hand has made me incredibly lazy about tasks of this nature. Also this was an introduction to the whole world of distance learning, library access, databases and refworks which was not something around in my youth. I do feel so much more competent for having tackled this. I believe I do understand what a systematic literature search is now which will be useful for me in the future.

## **The service evaluation**

The service evaluation was a very interesting thing to be involved with, and a difficult thing to write. I was caught up in the position of needing to react to a service demand while also using the same, to be part of my service evaluation. What started as a crusade in order to expand the service and get staff some help also needed to be presented into a reasonable evaluative study. This was the first part of the PsyD that I tackled and it took the brunt of all my lazy clinical ways. It ended up with me coming back to this again after I had completed all the rest having learned to evaluate things much more systematically and critically and eventually I hope I began to meet the task of writing it.

## **Concluding comments**

I hadn't thought about or realised how hard it would be to do this work on my own as a distance learner. I didn't have a peer group and started to ask my members of staff who had been trainees fairly recently about very practical things. There was a limit to how much I could do this though. Doing this on my own, meant that I didn't have access to the sort of banter about the process of doing the research in the way that you have as a trainee. And when I spent a few weeks not doing it because of other demands, I would lose the thread completely about where I had got up to and what I had planned to do. This was particularly the case with very practical things like the password to get into the library and different passwords for different data bases. I would put it in a notebook and then forget where I had put it, or maybe not even put it in, because I had used it a few times and didn't imagine I would forget. So this has been challenging due to a combination of being older and having lots of other life responsibilities and because I was just not used to focussing and thinking and being calm!

As I achieved different stages of the research process, my efforts hinged on the meeting of myself with my supervisor. I reflected with him one time that this process made me think about the process of going through psychotherapy. I definitely wanted to achieve this research goal which I believed would help me and make me a better person, whilst having no idea what that meant exactly. To achieve this objective I spent a lot of time thinking about how I did things and re doing them trying to find the 'right way'. I would attend monthly and sit with my supervisor, feeling delighted and devastated by turns by what he did say, might say, or what he could possibly mean.... One day I would achieve a new way of sitting with him and be pleased with my new self.

Overall I have learned a tremendous amount. It has been a steep learning curve. I have learned to be evaluative, systematic and more thorough. I have learned to exercise a greater humility in my dealings with clients. I hope I have learned to respect SSs and to listen to their accounts in a non expert way. I hope to do more.

## **Part 4**

### **Service Evaluation**

**Does the provision of a psychological service for NHS staff as part of in house Occupational Health Service result in measurable improvements in staff welfare?**

**A six month pilot study**

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## **Abstract**

This evaluation describes the establishment and provision of a six month psychological service for staff. This pilot was based within Occupational Health services for staff in an acute medical hospital alongside a physiotherapy service. Psychological services were offered as a brief treatment model. The service also provided consultancy and training to all levels of staff. Over the six months, 53 members of staff were seen for direct psychological consultation/treatment. Data were collected regarding professional group, and frequency of sessions and the effectiveness of the service on staff well-being was measured using the HADS as a measure of individual change. Organisational sickness absence data were gathered as a measure of the pilot's cost effectiveness within the organisation. During the pilot, data were also collected on the types of issues that staff presented with and the category of staff that attended. Results showed that staff anxiety decreased at a highly significant level, and depression at a significant level, but the level of returns of the questionnaires was very low. Staff sickness absence due to stress compared to the same six months of the previous year decreased by 40% resulting in substantial cost savings. Staff sickness across the division dropped from 5.29% to 3.87% over the 6 months. Staff reported sleep problems, low mood and emotional events as the most frequent issues that made them stressed, but loss of confidence in work role and being affected by events at work were also frequently reported; indicating the importance of a service linked in to the organisation. The treating psychologists reported bereavement issues as the most common treatment issue arising from users of the pilot. The evaluation is critically discussed and comparisons are made to published information about the national picture and recommendations made for future evaluation and research.



## **1. Introduction**

### **1.1 Health and well-being at work; the national situation**

Health and well-being at work have received increasing attention over the last few years. The National Director for Health and Work, Dame Carol Black, has been at the forefront of Well Being initiatives, leading the way with her report “*Working for a healthier tomorrow*” (2008), which focused on the health and wellbeing of the working age population. This publication highlighted the importance of creating a healthy workforce that benefits staff by endorsing the link between good work and good health. The report discusses factors that affect the working age population leading to losses in working days. Health behaviours such as smoking, drinking and obesity have a significant impact on health conditions in the working age population. Poor health outcomes related to these behaviours include high blood pressure, diabetes, coronary heart disease and respiratory diseases. Other common conditions discussed are mental illness and Musculoskeletal disorders, which along with cardio respiratory conditions accounted for two thirds of sickness absence, long term incapacity and early retirement.

### **1.2 Mental health and well-being at work**

Dame Black’s report cites a study (Gabbay & Shiels 2002) which undertook analysis of sick notes in the Merseyside area over a 12 month-period. This study showed that one in four people reporting in sick had a mental ill health diagnosis. Mental ill health accounted for over 40% of the total time covered by sick notes and the average time certified for a person with mental ill health (15 weeks) was twice as long as the average for all other conditions (8weeks). Mental health conditions were also identified as an important cause of lower productivity due to illness in the form of ‘presenteeism’. NHS Penninsula Medical School (2010) were commissioned to undertake a review of the

evidence base for early intervention in sickness absence. This review found that early intervention \*Occupational Health (OH) services can play a key role in assessing how and when employees can return to appropriate work because they offer holistic care within a biopsychosocial model.

Black's report led to a new conceptual understanding around fitness for work, and a number of practical changes were recommended including electronic medical certificates to change the 'sick note' to the 'fit note' and the emergence of a network of 115 NHS Occupational Health units to improve wellbeing service provision to staff within NHS Trusts.

### **1.3 Workplace stress**

The literature identifies staff wellbeing as important in both maintaining health care quality but also in reducing costs associated with poor care, absenteeism and changing workloads. Factors that contribute to support at work are clearly outlined in the Cochrane review (Van-Wyk 2010); which in turn lead to increased cost effectiveness in more efficient patient care.

The Department of Health went on to commission an independent review of health and wellbeing within the NHS specifically. This review (Boorman 2009) reported that 10.3 million working days were lost annually, through sickness absence alone, costing the NHS £1.7 billion. An average of 10.7 sick days per year were taken by health service staff compared with 9.7 days of staff in other parts of the public sector and with 6.4 days in the private sector. Nearly half of all NHS staff absence was accounted for by musculoskeletal disorders and more than a quarter by stress, depression and anxiety. NHS staff reported more work-related illness due to infectious

*\*Occupational Health abbreviated to OH throughout the text.*

diseases, stress, depression and anxiety than did workers in other sectors. The report made clear that mental health conditions are a major contributor to NHS staff sickness and that these issues are not always identified and tackled quickly and effectively. The Healthcare Commission's 2007 staff survey found that 33 per cent of staff questioned said they had felt unwell because of work-related stress over the past 12 months.

Identifiable 'stress' factors included; management practices, cultural practices such as long hours, high levels of bullying and harassment as well as the reluctance of staff to admit to such problems. .

The NHS Annual staff survey in 2007 reported bullying and harassment as major causes of stress at work; affecting 21% of staff, dropping to 18% in 2008. Bullying and harassment however does not appear to have fallen - a study by Durham university of 3,000 NHS staff in the north east of England, reported that around 20% of respondents reported being bullied at least 'now and then' within the past six months and 43% had witnessed other staff being bullied (Carter 2013).

Early self-referral for help for staff was recommended as a way to tackle these issues and other widely reported issues such as sleep deprivation, financial concerns and caring responsibilities outside of work which all contributed to stress levels in addition to general levels of stress from busy and demanding NHS jobs. Longer term NHS staff reported higher levels of stress as did those in managerial roles. NHS staff reported that they did not believe that NHS managers took a positive interest in their health and wellbeing. Other stressors reported by the Blackpool and Wyre Hospitals Trust in 2007 (cited in Boorman 2009) were excessive hours, restructuring, and again, bullying and harassment. The Boorman review (2009) made twenty recommendations which the government accepted in full, shortly followed by the publication of "*Ten Top Tips for Implementing Boorman for NHS Employers.*" NHS Employers also launched initiatives

to tackle the primary causes of sick leave; “*Back Pack*” (an education service for musculoskeletal disorders) and “*Open Your Mind*” (an educational service for mental health problems). NHS Employers’ ‘Open your mind’ campaign aimed to raise awareness of the stigma associated with mental health issues in the workplace and to encourage employers in the NHS to increase support for the numbers of people who suffer from severe mental health issues employed within the service (appendix U).

#### **1.4 Psychological interventions for staff working in health settings**

At the time of this evaluation, January to July 2011, there had been few published papers since 2000 describing evaluation of psychological interventions with health care staff, and of these, only one was in the UK (Wetzel, 2011). All of the published studies concerned the evaluation of secondary prevention staff support programmes for healthcare staff. These programmes aimed to reduce the severity or duration of experienced stress by helping employees manage job stress better through improved coping mechanisms. Included within this group were CBT based training; (Brunero, 2008; Galantino, 2005; Gardiner, 2004) mindfulness based training; (Krasner, 2009; Mackenzie, 2006; Pipe, 2009; Scenstrom, 2006; Shapiro, 2005) - which gave the largest and most promising improvements within a range of outcome measures); psychoeducational-based training, particularly targeting burnout (Le Blanc, 2007; Millstein, 2009) and stress management-based training which was undertaken with surgeons in the UK (Wetzel, 2011). All studies struggled with incorporating interventions into staff working schedules and lacked a coherent conceptualisation of staff wellbeing/stress. Sickness absence, and cost effectiveness/savings were wholly underrepresented, despite these being key factors in the Boorman review.

Questionnaires cited in the health and well being at work literature regarding staff sickness were not specific about the type of stresses that staff reported experiencing. Studies did however draw out a number of factors which contributed to staff feeling stressed. These factors were described as issues to do with: home, personal issues, organisational stressors, and interpersonal issues (Zeal report, 2011).

## **2. Health and well being Services for health staff locally. Setting up the psychological services for staff pilot.**

### **2.1 The local response to a national issue**

Substantial costs of staff absenteeism and prolonged staff disputes in NHS workplaces have led to NHS Trusts being increasingly required to demonstrate effective strategies for staff wellbeing at work. The conferring of trust foundation status includes a focus on quality as well as financial management – where patient and staff health and well-being have been highlighted as important (Monitor, July 2010). In this context, a decision was made at the acute medical hospital where the evaluation was conducted to provide the funding to set up a 2-day a week psychological service pilot within occupational health, which would be managed within their services. The hospitals ‘Health and wellbeing strategy group’ took responsibility for the overall management of the pilot study. As part of the health and well-being initiative the psychological service pilot and a physiotherapy service pilot were set up to run simultaneously. Within the trust there were 4 major divisions A, B, C and D (a pseudonym to protect confidentiality). Division B carried far greater sickness absence figures than the other divisions. The divisions’ rates of sickness absence were far higher than the national average and included high rates of ‘stress’. Division B therefore was particularly encouraged to use the pilot service and given priority over the other divisions in terms of access.

Prior to this pilot, the trust offered no psychological and some physiotherapy services for its 6,000 staff members. The director of \*Human Resources (HR), together with *\*Human Resources abbreviated to HR throughout the text*

OH, had agreed that during the six months of the pilot, data would be collected for the Trust concerning the impact of the pilot services on staff health and wellbeing and staff sickness absence.

The Trust board requested that the pilot be set up within the following two months from their decision to fund it, and so the running and evaluation of the project had to be decided upon very swiftly.

## **2.2 Allocation of staff, office and administrator**

The psychological service was run by two experienced psychologists, one of whom was the author, whose posts were backfilled throughout the 6-month period. The service was physically set up in an administration area of the medical school where it was quiet and away from clinical areas. An administrator who already worked within the OH department was asked to collect the pre and post data relating to the psychological services aspects of the pilot, keep a data base, give out appointments and send out questionnaires at all stages of the project.

## **2.3 Model of delivery and levels of intervention**

The psychological services delivery model mimicked the brief therapy and consultative models already employed by psychological services in clinical areas within the hospital, Utilizing a similar model, psychological interventions were offered to:

1. Staff members seeking help individually. Psychological help was offered in tandem with the work of the physiotherapist when there were co-occurring musculoskeletal issues.
2. Staff members who were in dispute with one another
3. Support and group interventions to groups of staff; working with clinical teams where there was conflict in order to promote clearer and more compassionate communication.
4. Support and education to managers, OH and HR regarding a psychological perspective on distressed staff and staff groups. The service provided psychological awareness training and supervision for HR and OH staff regarding anxiety and depression, psychological effects of trauma, and understanding and dealing with challenging personality types in the work place.

Interventions were delivered on the basis of need making good use of those psychological models shown by the literature to have been particularly helpful; i.e. cognitive-behavioural theory/therapy, mindfulness work, psycho-education and stress-management awareness through joint formulation. Up to a maximum of 6 sessions for individual work was anticipated.

## **2.4 Promoting awareness and realistic access to the psychological service pilot**

All Trust managers were sent a memo explaining about the Health and Wellbeing Pilot Study. This also explained that the pilot was primarily intended for Division B of the Trust (see appendix P). Managers were asked to refer staff members to OH for the pilot if they rang in sick with psychological problems such as stress or depression.

## **2.5 The referral pathway**

Referrals from managers to the OH service when they were for ‘The Psychological Services for Staff Pilot’ were marked ‘pilot’ with other identifiers (appendix Q). Staff were screened by the OH service using their usual protocols and sent to the service after completion of the pilot project questionnaires and consent forms. All group interventions and training work was similarly identified by OH but was not evaluated. All staff continued to be case-managed by OH.

### **3. Aims of the evaluation of the service**

The overall aim was to evaluate the service by implementing change measures with individual staff and then assess any cost savings to the organisation. The evaluative approach taken needed to utilise a pragmatic strategy given time constraints and resources whilst also using the opportunity to gather information about what staff were reporting as stressful in that particular Trust. Specifically then, measures were set up to include the following:

1. To gather data concerning which professional groups presented with psychological distress and consented to psychological help over the 6-month pilot; where they worked and how many sessions they attended.
2. To evaluate the effectiveness of the individual short-term psychological interventions used within the psychological service
3. To determine the impact of the psychological service on the number of days’ sickness and other relative costs to the division prior to and following the pilot project.
4. To gather information about what presenting staff understood as causing significant ‘stress’ to enhance understanding of this complex construct.



5. To gather information concerning the range of clinical issues encountered and the therapies utilized during the pilot project from the viewpoint of the treating clinicians.

## **4. Method**

### **4.1 Participants.**

A total of 56 members of staff were referred to the psychological service pilot from OH over the 6-month period of the evaluation. Of those referred, 53 attended and these staff members continued to be case-managed by the OH service.

### **4.2 Exclusions**

Staff were excluded from the service if they were currently under active psychiatric care and for whom psychological guidance was considered not to be useful, or if they already were receiving counselling or psychological therapy elsewhere.

## **5. Measures**

The measures used to evaluate the aims of the study were:

### **5.1 Demographic data.**

Basic demographic data and data on attendance were collected which included:

- 1) the number of sessions attended by individual members of staff utilizing the pilot psychological service.
- 2) which professional groups used the pilot
- 3) the percentage of staff who presented from Division B which was the target for the evaluation

This information was gathered from referral data which was collected by OH..

## **5.2 The Hospital Anxiety and Depression Scale**

The OH service already used the HADS screen (Hospital Anxiety and Depression Scale) in order to assess for anxiety and depression within their screening processes. This is an established screen that was first developed by Zigmond and Snaith in 1983. It loads on two factors that identify symptoms that are related to anxiety and depression. Each item on the 14- item questionnaire is scored from 0-3 and this means that a person can score between 0 and 21 for either anxiety or depression. Bjelland (2002) through a systematic review of a large number of studies identified a cut-off point of 8/21 for anxiety or depression. For anxiety (HADS-A) this gave a specificity of 0.78 and a sensitivity of 0.9. For depression (HADS-D) this gave a specificity of 0.79 and a sensitivity of 0.83. As this screen has been shown to perform well in assessing symptom severity and ‘caseness’ in anxiety and depression, in somatic, psychiatric, primary care and amongst the general population this was felt to be useful to continue to use within the pilot. The HADS data were collected by OH and analysed by the author.

## **5.3 Staff sickness data**

Sickness absence data were collected by HR through employment records.

- i) Incidence of sickness absence from work was calculated over the pilot study period.
- ii) Cost of sickness absence from work was calculated over the pilot study and compared with the cost of sickness data prior to the pilot study.

## **5.4 Subjective data about what stresses individual staff**

In the absence of a reliable questionnaire relating to staff stress; a 6-factor Likert scale screening questionnaire was developed as a rough and ready inhouse tool which was named the \**“Staff Stress Complexity Scale”* (SCSS) (appendix R). The items on this were developed from themes in the literature (appendix S), concerning stress related problems with:- physical health; interpersonal concerns with other staff ; personal stress, home-related stress; mental health difficulties; job role; and relationship with management. Two additional questions about stress related to ‘patient issues’ were included because experienced OH staff felt they were important.

This measure was used clinically to help in targeting interventions, given the need for short term work. The SCSS recorded the the number and extent of ‘stressors’ that referred staff were reporting. This was collected by OH and analysed by the author.

### **5.5 Psychological notes regarding staff issues brought to the sessions**

The psychologists kept a log regarding the issues addressed in the sessions. This was in order to collate more qualitative information regarding the kinds of clinical issues and the types of interventions undergone with staff throughout the pilot study.

## **6. Procedure**

Staff who were referred to the psychological service were interviewed and screened by OH and the HADS and SSCS were completed. Written consent was obtained from staff for their participation in the evaluation of the 6-month pilot project (appendix T).

Following the final psychological appointment, OH asked staff to repeat the HADS following their OH case review or this was requested by a questionnaire sent in the post.

*\*Staff Stress Complexity Scale abbreviated as SSCS throughout the text*

## **6.1 Ethical issues**

The two psychologists who ran the pilot project also worked within the acute medical Trust although they were employed by the local mental health Trust. Care was taken to explain parameters of confidentiality with users of the service. Assessment and treatment included discussion about how the intervention or recommendations would be fed back to OH; and where applicable, with managers. This collaborative process was seen as part of the work. All psychological information was kept confidential in the detail but with individual staff consent; reports, shared plans, and agreed ways forward within the health and wellbeing at work context, were shared with OH services. All detailed notes were kept separately and stored within psychological services.

It was understood that due to ethical considerations a control group for the evaluation was not possible. The only ‘control data’ would be from staff sickness prior to any service intervention.

## **7. Results**

At the end of the 6 months, the results were collated for presentation to the Trust Board. These results were organised in the same order as the initial aims and are detailed below with figures and tables to explain the data where helpful.

### **7.1. General information about individual staff seen during the pilot**

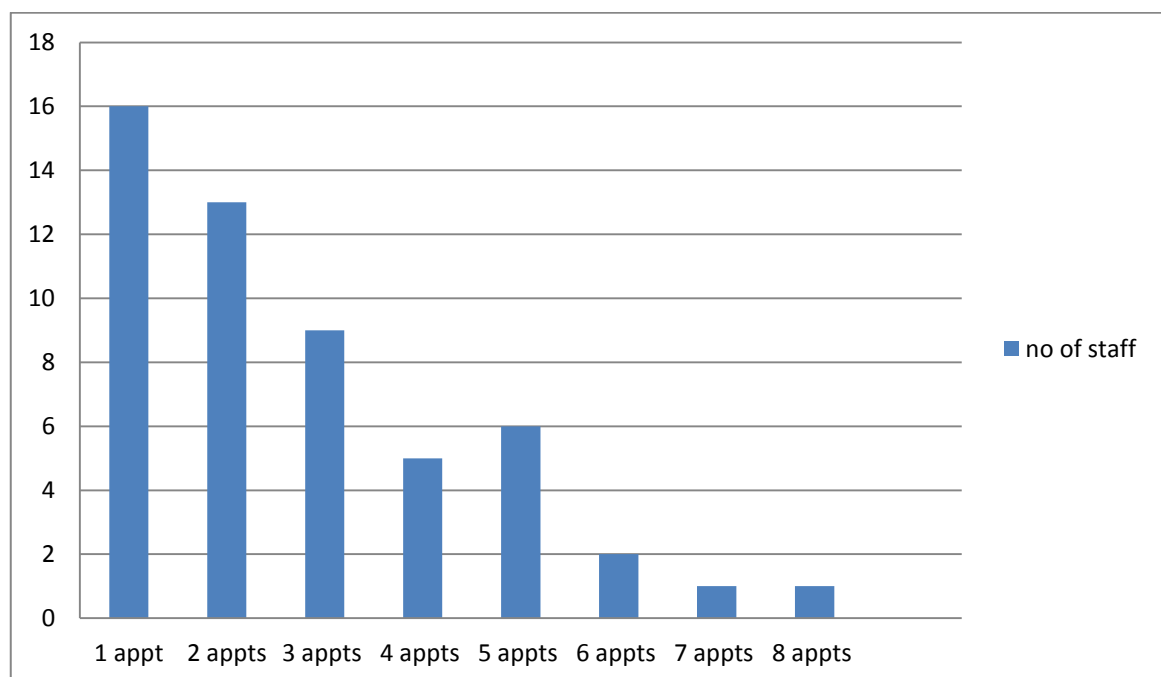
A total of 53 members of staff were seen individually throughout the pilot project. A further 3 were screened but did not attend.

The range of the number of appointments that were taken up by staff was between 1 and 16 as shown in **Figure 1**. The average was two to three appointments although ten staff

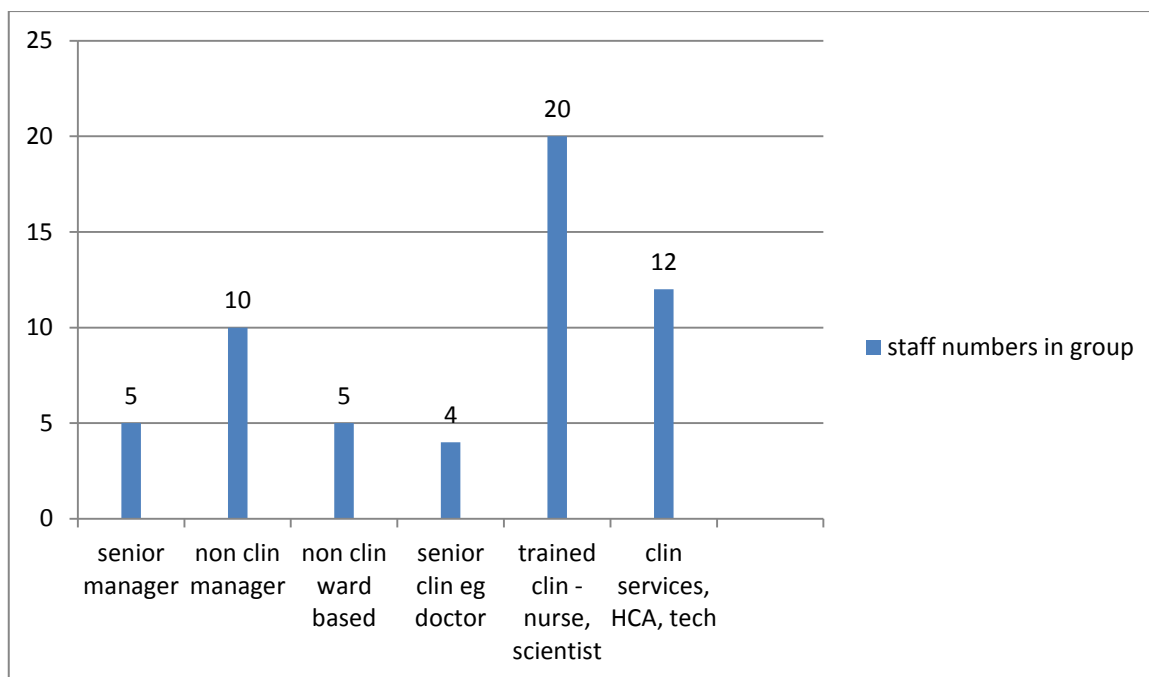
had more than five appointments while twenty nine staff had one to two appointments.

The majority of those attending used one or two sessions.

A wide range of professional staff used the psychological service and those professional groups were generally in proportion to service personnel; five were senior managers, ten non-clinical managers, five were non-clinical and ward-based, four were senior clinical staff, twenty were trained professional staff and twelve were non-professionally trained clinical services staff (**Figure2**). Of those that attended for individual work, 48% were from Division B; the division particularly targeted for the pilot study.



**Figure 1. Numbers of Appointments per staff Member.**



**Figure 2. Numbers within each staff group seen individually during the pilot.**

## 7.2 Evaluation of the HADS data.

Of the 53 staff who attended the service, 18 completed the pre and post HADS questionnaires, which was just over a third of the total; 34%. A further 33 attendees completed pre intervention HADS only with no post intervention HADS; and 2 attendees only completed post intervention HADS questionnaires.

Where the data were complete, pre- and post-intervention scores of reported anxiety and depression were analysed independently. A two-tailed paired T test was used to analyse statistical differences between the pre- and post-test scores.

The test as applied to pre- and post-measures of anxiety on the HADS, indicated a highly statistically significant difference between pre- and post-anxiety scores ( $p=.0065$ ).

The T test as applied to pre- and post-measures of depression on the HADS indicated a statistically significant difference to the pre- and post-depression scores ( $p < .05$ ).

Table 1. Shows the mean scores for the pre and post intervention data.

<b>Table 1 showing mean HADS depression and anxiety scores, and standard deviations, pre and post psychological intervention (n=18)</b>		
<b>HADS SCORES</b>	<b>PRE-INTERVENTION</b>	<b>POST-INTERVENTION</b>
Depression Score	9.42 (4.53)	6.24 (5.31)
Anxiety Score	12.68 (4.25)	9.40 (5.14)

The number of treatment sessions and improvement on the HADS scores were then analysed using a Spearman's correlation analysis. The analysis showed no significant relationship between the number of treatment sessions and change in combined anxiety/depression scores,  $r = 0.380$ ,  $p$  (one-tailed)  $> 0.05$ , although the association did approach significance ( $p = 0.060$ ). Therefore, the analysis was broken down into anxiety and depression scores separately. This subsequent analysis showed a significant association between the number of treatment sessions and change in anxiety scores,  $r = 0.508$ ,  $p$  (one-tailed)  $= 0.016$ . However, there was no significant association between the number of treatment sessions and change in depression scores,  $r = 0.247$ ,  $p$  (one-tailed)  $= 0.162$ . Previous t-tests showed that there were significant improvements in both anxiety and depression scores after treatment, indicating that treatment was successful in reducing both anxiety and depression across the group. However, the correlational analyses revealed that increased number of treatment sessions resulted in change in anxiety scores, and not change in depression scores. From those that

completed the HADS reduction in anxiety symptoms was related to the amount of treatment, whereas depression scores improved regardless of the number of sessions.

### 7.3 Staff sickness and cost of sickness

Data collected from HR showed the following. During the time of the pilot there had been over 200 referrals (for psychology and physiotherapy). Comparative sampling from the previous year January – July 2010 (table 2), showed 1370.48 Full Time Equivalent (FTE) fewer days had been lost for both ‘stress’ and MSK (musculoskeletal) issues; which resulted in a cost difference of £131,346.28. These costings concern the direct cost of absence and did not include the additional savings related to bank and agency expenditure which would have also been saved.

<b>Table 2. Showing stress and MSK sickness reporting and its cost, January – July in 2 consecutive years.</b>				
<b>Sickness Criteria</b>	<b>Days lost 01-07 2010</b>	<b>Days lost 01-07 2011</b>	<b>Difference in days Lost Jan – July 2010 compared with 2011</b>	<b>Cost savings difference in 2011 compared with 2010.</b>
‘Musculoskeletal’ issues (MSK)	1244.25	804.01	440.23 FTE fewer days lost	- £39,768.49
‘Psychological issues’(Stress)	2314.72	1384.47	930.25 FTE fewer days lost	- £91,577.79
<b>Total</b>	<b>3558.96</b>	<b>2188.48</b>	<b>1370.48 fewer days lost</b>	<b>- £131,346.28</b>

Table 2 shows that in division B the staff sickness days in 2011 compared with the same period in 2010 had decreased by 35% for MSK related absence and by 40% for stress-related absence.

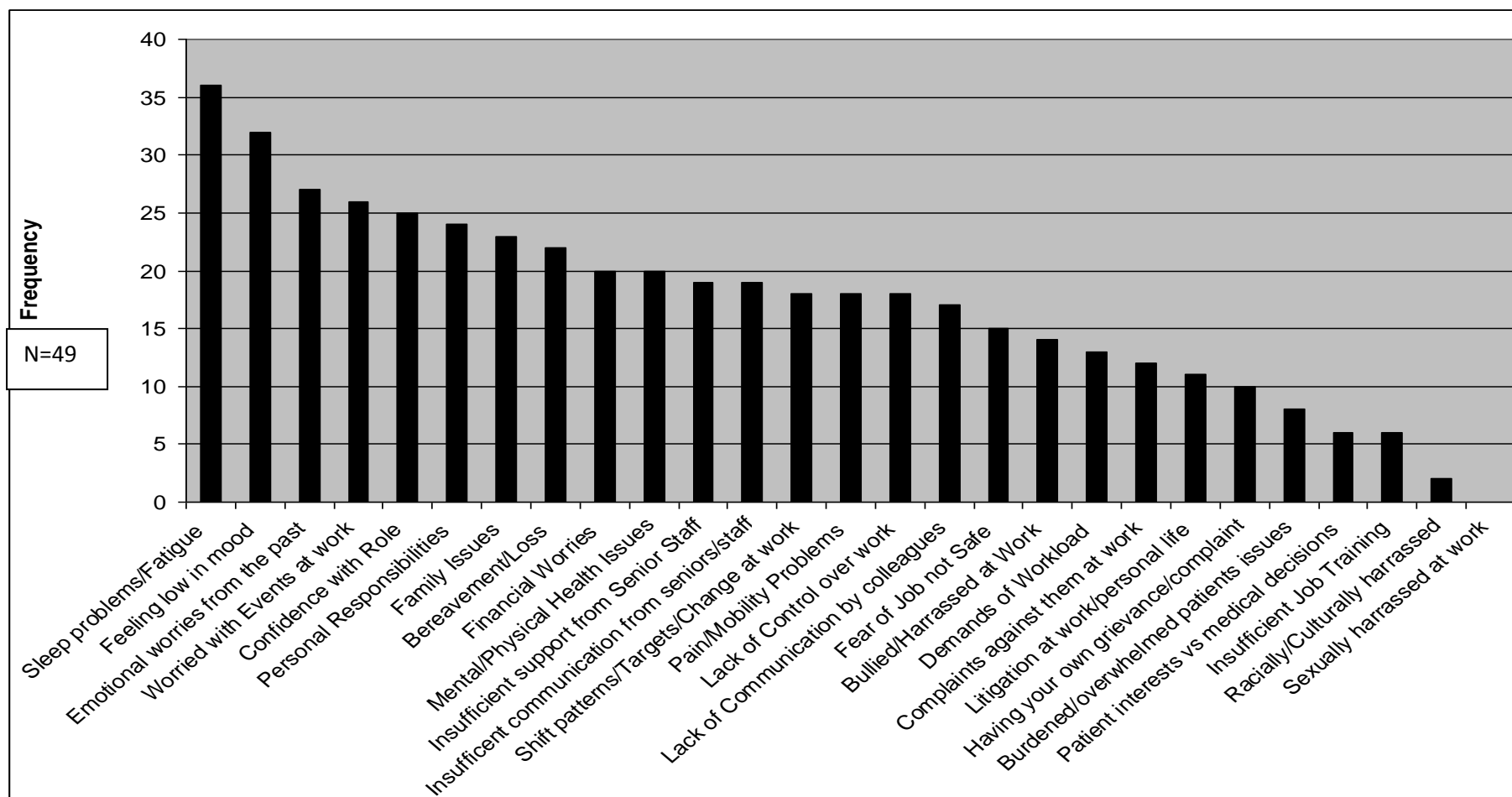
Overall the sickness/absence rate within Division B fell from 5.29% prior to the pilot study to 3.87% toward the end of the pilot study, (the national target for the following



year being 3.39%). There was a reported reduction of formal employee relations cases with a significant reduction on matters proceeding to employment tribunal (no figures were given).

#### **7.4 Staff ‘stress’ as reported on the SSCS**

The ratings of different stressors completed by 49 of those staff who used the pilot project are collated below in **Figure 3**. The graph shows which particular stress factors from the SSCS were rated as occurring often to everyday (on a Likert scale between 4-6); in order of frequency.



**Figure 3. Showing the most frequently reported issues on the staff stress complexity scale**

## 8. Discussion of Results

*Did those that attended for individual intervention improve their psychological health and wellbeing?*

Since the 1990's there has been an increasing literature about the role of stress at all staff levels (including doctors) in the NHS (e.g. Firth-Cozens, 2003) and this range of staff was well represented during the pilot. The intention was to collect pre- and post-HADS for all users of the service and not just those from Division B, so it stood as a separate measure from that collected by HR.

The statistical analysis of pre- and post- differences in anxiety and depression in this evaluation showed that experiences of these mood states had changed significantly after psychological intervention and that a higher number of sessions was related to a lowering of anxiety. This result however is an extremely low representation of those that used the service. The return rate of post- intervention HADS questionnaires was extremely low (n=18), which meant that the immediate outcomes of two thirds of those receiving interventions was not known.

As the 18 results are so positive regarding the improvement in anxiety, (some of which occurred during case review), it may have been that those staff who benefited from the pilot, made the effort to return the HADS as they felt better and perceived the acknowledgement of this as important.

Many of the post- HADS questionnaires were sent out in the post. The rate of the return of those post-intervention questionnaires was much lower than would be expected.

Cummings (2005), cited that the average response rate for postal physician questionnaires, where some relationship to responders might be expected, was 61%, as

compared with the average response rate for large sample surveys (> 1,000 observations) which is just over 52%. Edwards (2002) in a review of factors that encourage the return of questionnaires reported how monetary incentives, short questionnaires, personalised questionnaires, recorded delivery, first class post and contacting participants before sending out the questionnaires, increased the response; whereas questionnaires of a more sensitive nature were less likely to be returned (Edwards, 2002). The author was not party to the sending out of the post-HADS forms in order to assess if any of these more helpful factors were present. In this evaluation, no systematic or personalised approach had been devised and therefore was not implemented, regarding the practical process of collecting and collating post-treatment HADS questionnaires. A large quantity of important information was not collected, which would have given much clearer validity about immediate treatment outcomes.

Another factor that may have influenced post-HADS questionnaire return is the way that staff may have perceived the service. Access to the project was via an OH and manager referral as part of case management and staff gave consent to that service being evaluated. This would have affected staff's perception of the service as their use of the service was also in effect being evaluated. Staff were not gaining assistance anonymously as would occur in a self-referring employment assistance programme (Hughes, 2007). Giving information concerning psychological health after intervention may have been something that many staff were unwilling to share.

*Were there improvements in staff sickness and the cost of staff sickness in Division B of the Hospital?*

Significant reduction in staff stress absence occurred within Division B over the 6 month pilot with a 40% difference in staff sickness absence compared to the same period a year earlier.

Division B carried a higher than average rate of sickness and 'stress' as the reason for

sickness in comparison with MSK seems to have been unusually high. Amongst the most commonly nationally reported causes of sickness absence for manual workers, (CIPD, 2010) MSK and back pain has a far higher incidence (up to 66%) than stress and home/family issues (34 – 44%); whilst for non-manual workers, stress and home issues are reported more frequently (37-55%) compared with MSK and back pain (44-53%). Nationally, MSK and back pain staff sickness tends to be higher than ‘stress-related’ sickness absence. In Division B taking MSK and ‘stress’ sickness together, ‘stress’ resulted in 65% of the total in 2010 reducing to 63% over the pilot.

The figures presented by HR show that there was a 40% improvement in ‘stress-related’ days lost within Division B, compared with the same 6 months of the previous year and overall the sickness rate in that division dropped from 5.29 to 3.87.

The national annual sickness absence rate had fallen progressively up until 2012. Reported sickness in 2009-10 was 4.40%; 4.16% in 2010-11; and 4.12% 2011-12. (Health and Social Care Information Centre, 2013).

It would appear therefore that there was a definite difference in sickness rates over the 6 months of the pilot compared to the previous year that was greater than the national average, even though the stress sickness rate within Division B was extremely high. The HR director’s comment was “....we cannot attribute all reductions in absence to the pilot study but given the number of related referrals it is reasonable to believe that this had a significant impact”.

A major factor in the implementation of the pilot and the well-being initiatives were the OH nursing team. The team were well known and respected throughout the Trust and the pilot was known to be their initiative. These nurses were often seen on the ward areas and in different parts of the hospital and were trusted by all grades of staff. As part of well-being initiatives, OH nurses were also involved in the implementation of a computer assisted lifestyle management (CALM) program for employees, involving 25 staff in a Global Corporate Challenge event and in organising health and well-being

open days for Trust employees, offering health and lifestyle advice, information and free healthy eating snacks.

It is reasonable to speculate that something of a 'Hawthorne effect' (Parsons, 1974) may have occurred. In this study which took place at the Hawthorne factory, short term productivity gains were made that were apparently due to the motivational effect on the workers of the interest being shown in them.

Where NHS staff have felt that their concerns have been taken seriously both individually and more systemically studies have shown how this has helped contribute to staff feeling supported (Van-Wyk, 2010) and contributes to a lowering of staff stress levels.

Managerial leadership style has been shown to affect staff satisfaction levels and levels of stress and sickness absence (Clegg, 2001). The importance of this issue has led to NHS guidelines and 'tools' addressing working with staff perception and 'how to listen' (NHS institute of innovation and improvement, 2008) in order to improve health and well being.

In addition, the pilot gave support to HR which was acknowledged by them, and this helped to manage issues for employees and HR before they become problems and before problems led to sickness absence (Hughes 2007).

*What information was gathered about significant stress for staff in this particular Trust?*

The SSCS was reported by the psychologists to be useful clinically. Difficulties in sleeping was the predominant stress factor (rated by 73% of staff) and this has been widely reported as a prominent issue within the literature on staff stress. Sleep deprivation alongside financial worries (rated by 50% of staff) and caring responsibilities outside of work (rated by 49% of staff) has been widely reported in the literature (Boorman, 2009). The issue of sleep deprivation has included doctors

working extremely long hours and nurses working extended shift patterns (Firth-Cozens 2003). Difficulties in sleeping however also occurs as a significant symptom of anxiety and depression. Weinburg (2000) found that taking into account staff who might be personally vulnerable to psychological disorder, even when there was on-going social stress outside of work, it was stressful situations at work that significantly contributed to anxiety and depressive disorders affecting sickness absence. Nationally, 33% of staff felt stressed by management and cultural practices in the NHS (healthcare commission, 2007) and this may be reflected in 53% of the staff in this evaluation noting 'finding yourself preoccupied with one or more events at work,' and 51% 'feeling a lack of confidence in working role', as something that occurs for them 'often to everyday'. Nationally, bullying and harassment has been reported as an issue for around 20% of NHS staff (Carter, 2013) and this was cited as an 'often to everyday' factor for 28% of the staff in this pilot study. The heads of the project had also anticipated patient issues as a factor in staff stress (not reported elsewhere) but this proved not to be the case. So overall these stress factors reported were very similar to the national picture.

The psychologists who worked on the pilot reported that the most frequent clinical issue they encountered was bereavement and long term complex grief. It has been argued that this emotional state is separate from anxiety and depression (Boelen, 2007) and can profoundly affect mental health and quality of life. On the SSCS – 45% of staff had reported that personal loss, bereavement or health adjustment was an often to everyday issue for them. This however did not appear to reflect the issue of prolonged and complicated grief reported by the psychologists. This issue is not something that the literature has particularly commented upon to date. The treating psychologists reported that staff seen by the pilot close to the time of a new episode of psychological distress were able to be helped much more quickly than those who had been struggling with no support for much longer. Seeing staff members sooner meant that staff had resources to engage in strategies and problem solving and could engage more with how a plan was

made to return to work. This has since been recommended within NHS settings (NHS direct 2012 – trigger points).

*What were the limitations of the evaluation?*

The psychological pilot service had to be set up within a short space of time, so there were many things about its evaluation that could have been improved.

Lack of a dedicated administrator or a clear strategy for post-HADS collection meant that data collection was haphazard.

Although individual psychological interventions were reported as helpful, there was a paucity of data to support this.

As the pilot only lasted 6 months, longer term follow up was not possible in order to ascertain whether such short term work had an enduring effect.

Systematic collection concerning other interventions offered such as training and consultancy support would have provided evidence concerning the impact of the pilot. Similarly, some way of assessing the value of an in-house service as opposed to an external one would have provided evidence for the Trust in reviewing how to invest in future services. A loosely structured staff satisfaction survey would have been helpful to gain staff's ideas on what they found helpful about the psychological service, whether an external service might have been preferable, and would have helped inform the Trust about what tertiary/psychoeducational sessions might be useful to offer more widely to Trust employees.

## **9. Recommendations for the future and further studies**

Evaluating training for managers in how to support staff to come forward for psychological support, would help to create more discourses within the NHS about signs of psychological stress so that staff could be helped and supported nearer to the point of finding things difficult. Published studies have offered mindfulness and self-



management using CBT in order to promote psychological resilience and more of these are needed within NHS UK. Evaluation regarding focussed information giving and psycho education on understanding anxiety and depression, sleep hygiene and coping with bereavement are indicated from this study.

In line with the Cochrane Report if staff stress is lowered then greater efficiency should be expected in the health care delivered. This is another domain in which cost savings could be measured and would be important in further studies.

## **10. Conclusions**

This evaluation showed that within an NHS division with a high degree of sickness from stress, over a 6-month piloted service, significant improvements occurred in the costs of staff sickness. The service was used by a wide sector of the personnel and the majority utilized one or 2 sessions. There were significant improvements reported in anxiety and depression from those that did fill in pre- and post-HADS questionnaires, but the response rate was very low. That the pilot was a part of OH may not have helped with the HADS questionnaire return rate, as staff may have felt they were being evaluated. The pilot project was seen as a significant factor in the lowering of staff sickness and this was possibly because the pilot occurred within the context of a health and well-being initiative championed by OH that demonstrated care and attention toward staff. The stress evaluation tool was anecdotally helpful to the clinicians and demonstrated similar reported stresses to those that have been nationally reported. Amongst the top five difficulties, 'being affected by events at work' and 'not being confident in the working role' featured as occurring 'often to everyday' highlighting the importance of work place psychological services being linked into the wider organisational service.

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# Appendix P

## Health and Well Being Pilot Study

As part of the government Health and Wellbeing agenda, the hospital has developed a strategy to support our staff with the management of:

- Musculoskeletal Disorders and
- Psychological issues for staff.

These particular conditions have been highlighted for additional support as they are the two most common conditions that contribute to staff sickness rates and also referrals to occupational health.

Therefore a 6 month pilot of fast track physiotherapy and psychological intervention will be initiated from January. The pilot is primarily intended for Division B. However, other areas will be considered depending on priority.

As a manager/ supervisor both areas will allow you to:

1. Refer members of staff for 1-1 assessment and onward referral
2. In addition, for the psychological services, it is intended that this can support individuals and also teams.

### **Who to refer:**

Referrals to the pilot are via email marked 'PILOT' to the generic Occupational Health email address.

The information required on the referral is as follows:

Name:

DOS:

Department:

Job Title:

Contact Number work:

Contact number home/mobile:

Absent from work: Yes/No

### **What now?**

The member of staff will be contacted via telephone or offered an Occupational Health Appointment and offered evidence based guidance on management of their condition.

Where required, they will be offered an appointment with a treating physiotherapist/psychologist. If referred for treatment the manager will be notified by email. Where required, guidance will be given, concerning modified duties with informed consent of the employee.

**Your co-operation and support in allowing staff to attend appointments is appreciated.**

## **Appendix Q**

### **Psychological Service Referral in Occupational Health**

**Name:**

**Address:**

**Date of Birth:**

**Telephone No:**

**Cohort No:**

**Department:**

**Job title:**

**Seen by GP:**

**Last review date:**

**Medication:**

**Absent from work**

**Yes**

**No**

**How long?**

**Stress complexity and HADs form attached?**

**Relevant additional information:**

**What client expect from Psychological referral:**

**Date of review appointment with OH:**

**Signature of client:**

**Signature of referrer:**

**Date:**

# Appendix R

## STRESS COMPLEXITY SCALE

Work Location .....

Name/Initials .....

Work Role .....

Date .....

Below are a number of reasons people can experience stress that affects their working life. Please indicate which areas are currently affecting you by using the 0 – 6 scale below. This scale is in order for us to collect better information about what staff are experiencing. It does not mean you will be expected to explain your responses unless you want to do so.

0	1	2	3	4	5	6
Never	Almost Never	Rarely	Sometimes	Often	Very Often	Everyday

Taking on extra or different responsibilities in your personal life that take a lot of energy		Lack of communication or miscommunication by seniors/staff.	
Coping with personal loss, bereavement or health adjustment		Lack of communication or miscommunication with colleagues.	
Feeling a lack of confidence in working role or being asked to work beyond capabilities or other role related issues.		Financial worries	
Feeling sad, fearful, low in mood or traumatised by many or one incident.		Having things that still trouble you emotionally from the past.	
Having to deal with persistent family issues.		Dealing with complaints against you or your area of work.	
Having mental health problems that are difficult to deal with.		Putting through your own complaint or grievance.	
Having problems sleeping or with fatigue.		Having to cope with litigation at work or in personal life.	
Having pain or mobility problems.		Feeling bullied or harassed at work.	
Being asked to meet targets, change shift patterns etc.		Feeling sexually harassed at work.	
Finding yourself worried or preoccupied by one or more events at work.		Feeling racially or culturally harassed at work.	
Feeling burdened or overwhelmed by patients' issues.		Finding yourself caught between what you feel is patients' best interests and medical decisions.	
Worried your job is not safe.		Feeling the demands of your work are too great to deal with	
Feeling you have lack of control over your work		Feeling you have insufficient training to do your job	
Feeling insufficiently supported by Trust/senior staff/colleagues		Other .....	

Please explain any of these factors further if you would like to:-

.....  
 .....



## Appendix S

<b>Showing staff stress factors reported in the literature and the questions on the SSCS.</b> <b>These appear in the order reported in this study.</b>	
<b>REPORTED STAFF STRESSORS FROM THE LITERATURE</b>	<b>QUESTIONS ON THE STAFF STRESS COMPLEXITY SCALE</b>
Personal issues, mental health, Sleeping problems	"Having problems with sleeping or with fatigue"
Mental Health, Depression and anxiety	"Feeling low in mood"
Mental Health	"Having things that still trouble you from the past"
Work related stress, Job Issues	"Finding yourself preoccupied by one or more events at work"
Work related stress, Job Issues, Busy and demanding NHS	"Feeling a lack of confidence in working role"
Home issues, Personal issues, Caring responsibilities	"Taking on extra or personal responsibilities in your personal life that take a lot of energy."
Home Issues, Personal issues	"Having to deal with persistent family issues"
Mental Health	"Coping with personal loss, bereavement or health adjustment"
Home issues, Personal Issues Financial concerns.	"Financial worries"
Mental Health, Severe mental health problems	"Mental health problems that are difficult to deal with"
Management /organisation practices	"Feeling insufficient support by trust senior staff and colleagues"
Management organisation practices	"Lack of communication or miscommunication by senior staff"
Management organisation practices, Restructuring	"Being asked to meet targets, change shift patterns etc"
Physical Health	"Having pain or mobility problems"
Work related stress, Job Issues	"Feeling you have a lack of control over your work"
Interpersonal Issues, Staff issues, reluctance of staff to admit to problems	"Lack of communication or miscommunication with colleagues"
Work related stress, Job Issues	"Worried your job is not safe"
Interpersonal Issues at work, High levels of bullying and harassment	"Feeling bullied or harassed at work"
Work related stress, Job Issues, Excessive hours	"Feeling the demands of your work are too great to deal with"

Work related stress, Job Issues	"Dealing with complaints against you or your area of work"
Work related stress, Job Issues	"Having to cope with litigation at work or in personal life"
Work related stress, Job Issues	"Putting through your own complaint or grievance"
Not covered in the literature - Patient issues	"Feeling burdened or overwhelmed by patient issues"
Not covered in the literature - Patient issues	"Finding yourself caught between what you feel is patients best interest and medical decisions"
Work related stress, Job Issues	"Feeling you have insufficient training to do your job"
Interpersonal Issues at work	"Feeling racially and culturally harassed at work"
Interpersonal Issues at work	"Feeling sexually harassed at work"

# **Appendix T**

## **Written consent form**

### **Psychological Service Referral in Occupational health**

**Name:**

**Address:**

**Date of Birth:**

**Telephone No:**

**Department:**

**Job title:**

**Medication:**

**Absent from work**

**Yes  
How long?**

**No**

**I consent to an assessment from the pilot psychological service.  
I understand that this is a confidential service, and that information discussed  
during the sessions will not be made directly available to my employer without  
my consent.**

**Date of review appointment with OH:**

**Signature of client:**

**Date**

## Appendix U

### **NHS employers open your mind campaign.**

NHS Employers Open Your Mind Campaign, continues to have a remit for supporting NHS organisations by –

- Supporting managers in identifying and managing the causes and effects of stress in the NHS workforce
- Helping to minimise the levels of stress in the NHS workforce and its impact on the lives of staff and healthcare delivery
- Reducing the personal and financial impact of workplace stress on staff.
- Working with NHS organisations and particularly their employees to identify causes and their potential remedies
- Identifying causes of stress which are common to all types of trusts
- Identifying the potential for further work that could be developed across trusts nationally.

# Other Appendices

## Appendix V

### **The Authors Epistemological Position**

The author's relationship with Stroke Survivors has been based on working as a professional Clinical Neuropsychologist in the field of stroke recovery for 10 years, mainly in acute and early rehabilitation. A Neuropsychologist is required to be frequently engaged with assessing for the deficits incurred after stroke in order to make recommendations and facilitate processes within stroke rehabilitation. The choice of research topic came from a lack of information about social cognition issues in stroke recovery, or any established way of assessing it, and a desire to promote discourses about challenges in social relationships for stroke SSs within the stroke community. Clinical experience indicated that many SSs had social cognition problems following stroke but that it was hard to engage clients concerning this subject. The author's philosophical standpoint concurs with "the ethics of care" (Held 2006) sometimes known as "relational ethics" (Ellis 2007). The main philosophical standpoint of "ethics of care" is the understanding that individuals and groups participate in a dynamic and on-going construction of themselves through their relationships with others. It is the care involved in these relationships which are crucial in creating a shared understanding of perceived social reality and allows for growth, nurturance and safety. The author clinically utilizes a relational perspective in her work based on attachment theory, with an understanding of the psychosocial and neuro-biological basis of attachment patterns; and how these are brought into play following physical health and brain injury trauma.

# Appendix W

## Chronology of research process

**July – December 2011:** *Research Proposal development*

**January 2012:** *Sponsorship Approval from Leicester University*

**February 2012:** *Submission for NHS NW REC ethical approval, through the IRAS system*

**March 2012:** *Ethical approval given; dependent on changes to consent and information forms.*

**April 2012:** *Full ethical approval granted for study with version 2 consent and information forms.*

**April 2012:** *Local PI status given from local NHS trust.*

**July – October 2012:** *Research participants sought, recruited and interviews undertaken.*

**November – December 2012:** *Transcripts typed out, and the initial process of engaging with the data began.*

**February – April 2013:** *Transcripts analysed and thematic analysis carried out.*

**May – August 2013:** *Write up of results and discussion of results to complete research study.*

**October – November 2013:** *Collation of thesis and submission of research for PsyD.*

# Appendix X

## Journal submission guidelines

### Topics in Stroke Rehabilitation

#### Instructions for Authors

##### **Purpose of the journal**

*Topics in Stroke Rehabilitation (TSR)* is an interdisciplinary journal devoted to the study and dissemination of practical and theoretical information related to the subject of stroke rehabilitation. The journal reviews and reports on clinical practices, state-of-the-art concepts, and new developments in stroke patient care and research. Both primary research papers and comprehensive reviews of existing literature are included. The objective of each issue is to summarize and synthesize current knowledge on a selected timely topic in stroke rehabilitation.

##### **Manuscript submission**

*TSR* uses the Editorial Manager online manuscript submission system. A brief registration is required. **Forms and further information are available on the Editorial Manager system.**

*TSR* endorses the Declaration of Helsinki and assumes that authors of papers submitted to *TSR* will have followed all ethical and legal standards for pursuing original experiments on human beings as determined by their institutions.

##### **Manuscript review process**

All manuscripts are reviewed by one of the Editors and at least two outside reviewers for clinical relevance, originality, scientific quality, and statistical accuracy.

##### **Manuscript preparation**

Submissions are limited to a 3,500 word length without prior permission from the Editor (tsreditor@thomasland.com). Microsoft Word (6.0 or higher) is the preferred software. Manuscripts should be double-spaced (including quotations, lists, references, footnotes, figure captions, and all parts of tables). Manuscripts should be ordered as follows: title page, abstracts, text, references, appendixes, tables, and any illustrations. Number pages consecutively. Research Articles and Clinical Studies should consist of the following sections: abstract, at least three and up to seven key words, introduction, methods, results, discussion, conclusion, acknowledgments, and references.

## Copyright

Authors must release copyright ownership of their manuscript at the time of its submission. A Copyright Release form (available in Editorial Manager) must accompany the manuscript before processing for publication can begin. It is understood that articles submitted to be published in *TSR* will not be submitted to any other publication.

## Submission checklist

Each submission must include the following:

1. Title page including (1) title of the article, (2) author names (with highest academic degrees) and affiliations (including titles, departments, and name and location of institutions of primary employment), (3) any acknowledgments, credits, or disclaimers, and (4) a shortened title (maximum 45 characters) for use as a running head.
2. Abstract of no more than 250 words and up to 7 key words that describe the contents of the article like those that appear in the *Cumulative Index to Nursing and Allied Health Literature* (CINAHL) or the National Library of Medicine's Medical Subject Headings (MeSH). For abstracts of Research Articles and Clinical Studies, please include background, objective, methods, results, and conclusions sections.
3. Clear indication of the placement of all tables and figures in text.
4. Signed Copyright Release Form.
5. Written permission for any borrowed text, tables, or figures.

## References

Cite references in text and style in the reference list according to the *American Medical Association Manual of Style*, 10th ed. They should be numbered consecutively in the order they are cited; reference numbers can be used more than once throughout an article. **References should not be created using Microsoft Word's automatic footnote/endnote feature.** References should be included on a separate page at the end of the article and should be double-spaced.

## Tables

Include tables on a separate page at the end of the manuscript, not embedded in the manuscript. Number tables consecutively and call out each one in text. Supply a brief title for each table. Type explanatory statements, notes, or keys below the table. Explain in footnotes all nonstandard abbreviations. For footnote labels, use lowercase letters a, b, c, etc. Type source and permission lines below the table. Type credit lines exactly as requested by the original copyright holder.

## Illustrations

High-resolution figures can be submitted electronically as either a TIFF or JPEG file



with at least 300 dpi. Save and submit files in both the application in which they were created (i.e., Adobe Illustrator, Corel Draw and Photoshop) and as either JPEG or TIFF files. We do **not** accept art that is in color, is embedded in the text, was downloaded from the Internet, or has been photocopied. Cite each figure in the text in consecutive order. Supply a caption for each figure. Captions should include the figure title; explanatory statements, notes, or keys; and source and permission lines. If a figure has been previously published, in part or in total, acknowledge the original source and submit written permission from the copyright holder to reproduce or adapt the material.

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