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STROKE PATIENTS AND THEIR PARTNER'S PERCEPTIONS OF SURVIVOR FUNCTIONING

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SUMMARY

Background: Research into stroke survivors and their partners have shown that the partner frequently rates the stroke survivor as less capable than the survivors rate themselves through self-report questionnaires or qualitative interviews; however, no research to date has used cognitive tasks as a method for investigation. This paper aims to investigate if the stroke survivor or the partner rate the stroke survivor as worse across all cognitive domains.

Material/ Methods: This research aimed to observe the incongruence of stroke survivors and their spouse's perception of survivor functioning by rating their confidence on Picture Memory, Verbal Memory, Digit Span, Luria's Three Step Test, NART and Raven's Matrices. Participants, and to compare these score to see if either could predict the actual score.

Results: Showed that neither the stroke survivor nor the partner consistently rated functioning as worse, but there was a significant difference between the dyad. Further, the stroke survivor and the partner's confidence had no relationship with raw scores. A thematic analysis was also conducted and themes emerged from the data. These were "Confidence," "Insight into Ability," and "Post-Stroke Changes."

Conclusions: These themes were shown to interlink with the scores provided in the qualitative analysis, and implied that low self-efficacy may be crucial in post stroke recovery. Limitations and implications are discussed in full.

Key words: stroke, rehabilitation, couples, incongruence, Self-efficacy, cognition, caregivers

BACKGROUND

A stroke is characterized as a neurological deficit caused by an acute focal injury to the central nervous system by a vascular cause, including intracerebral hemorrhage, a subarachnoid hemorrhage and cerebral infarction. Worldwide, stroke is one of the leading causes of death (Lopez, Mathers, Ezzati, Jamison, & Murray, 2006) and a primary reason underpinning long-term neurological disability in adults — with more than half of all survivors being left dependent on caregivers to help them with menial activities (Wolfe, 2000). The current concern is our rapidly ageing population and the urgent need to promote successful ageing (Riby, 2016). By 2013, 6.4 million people died of stroke in the developed countries, with the death toll set to rise to around 12 million by 2030, with 70 million stroke survivors by 2030. The impact of stroke is global upon the patient, resulting in increased depression and neurological disorders (Wolfe, 2000), reduced physical activity (Saunders, Sanderson, Bazzelli, Grieg, & Mead, 2013; Smith, Saunders, & Mead 2012) and cognitive impairments that compromise the performance on the everyday tasks of daily living (Cho, & Lee, 2012; Claesson, Lindén, Skoog, & Blomstrand, 2005; Mayo, Wood-Dauphinee, Cote, Durcan, & Carlton, 2002).

The post-stroke recovery process is moving to focus on social support and structure, suggesting rehabilitation within the home environment is more beneficial (Visser-Meily, van Heugten, Post, Schepers, & Linderman, 2006). Tsouna-Hadjis, Vemmos, Zakopoulos, & Stamatelopoulos (2000) found evidence that the quantity of family support received by stroke patients significantly influenced changes in the ability to undertake daily activities and improved mood and depression status in the first six months after having a stroke. Furthermore, those who were classed as more severely impaired were found to have a greater amount of functional improvement if high level support was present. Successful rehabilitation outcomes are strongly linked with both high patient and family motivation (Langhorne, Bernhardt, & Kwakkel, 2011). This assertion has also been enforced by Mayo, et al. (2000), whose results state that those who are discharged and cared for at home have more functional gains through natural recovery and, in turn, have a greater degree of function and satisfaction. Whilst home-based rehabilitation encourages the aforementioned factors, it has shown to be equally successful as hospital-based rehabilitation, which causes less strain on the caregiver. Anderson et al. (2000) found that caregivers who provided home-based rehabilitation scored lower on self-reported general health status than those caregivers within hospital-based rehabilitation. There is a large body of literature which shows that caregivers are put under enormous strain and consequently damage to their overall mental health (Haley, Roth, Hovater, & Clay, 2015; Grant, Hunt, & Steadman, 2014; Northcott, Moss, Harrison, & Hilari, 2015; Oosterveer, Mishre, van Oort, Bodde, & Aerden, 2014). Pinquart and Sörensen's (2003) meta-analysis showed that those who care for a frail, older adult were found to suffer from higher levels of stress, depression, decreased self-efficacy and lower overall well-being and physical health, placing a great strain on the family unit.

As the primary caregiver in the home environment is frequently the spouse (Allen, Goldscheider, & Ciambrone, 1999), relationship strain often develops after a stroke. When mild cognitive impairment is presented, Garand et al. (2007) noted that anomalous behaviours presented by the affected person may be seen as distressing to the spouse, degrading the marriage quality substantially. Compared to participants who were unmarried and living with their family, married stroke survivors showed a poorer outcome in their overall mental health and quality of life (Ostwald, Bernal, Cron, & Godwin, 2015), whereas unmarried stroke sufferers coped significantly better with their impairments (Kauhanen, et al. 2000). Many studies have displayed that those who have suffered a traumatic brain injury are more likely to have a divorce (see Dijkers, 2004, for a full review). Thompson and Ryan (2009) investigated the subjective impact of stroke on the spousal relationship and found that the strain is complex and multi-faceted. Stroke survivors reported that they often display high levels of anger and frustration over their dependence on their spouse and the guilt that it causes. They report a loss of identity and their sense of self, relinquishing the predefined roles within the marriage partnership. The focus of stroke rehabilitation needs to be modified from a patient-focused approach to a dual-role responsibility of patient and caregiver (McCullagh, Brigstocke, Donaldson, & Karla, 2005). To do this, practices must be put in place to ensure that caregiver satisfaction remains somewhat equal to the rest of the population. Successful reduction in caregiver strain was shown to be most successful if provided with counselling (see Visser-Meily, van Heugten, Post, Schepers & Linderman, 2005, for a full review; see also Umegaki et al., 2014).

Many studies which look at cognitive deficits seen in post-stroke use the Mini-Mental State Examination (Pendlebury, Cuthbertson, Welch, Mehta, & Rothwell, 2010; Zwecker, et al., 2002; Rasquin, Verhey, van Oostenbrugge, Lousberg, & Lodder, 2004), but this measure has been widely criticized for its inability to measure specific cognitive deficits (Bour, Rasquin, Boreas, Limburg, & Verhey, 2010). Hurford, Charidimou, Fox, Cipolotti and Werring (2013) discussed how there is a paucity of research that shows detailed cognitive impairment after acute strokes. Although dysphasia and neglect are routinely assessed as part of the rehabilitation process; cognitive impairments which may be more subtle in everyday life are largely not part of any such assessment. It is critical in planning rehabilitation strategies that these impairments are monitored for deterioration as they are exemplary predictors of long-term cognitive and functional outcome (Nys, et al., 2005). McCarthy and Lyons (2015) provided an in-depth mixed-methods study which investigated the incongruence of beliefs seen in spouse perceptions of survivor functioning. Quantitative data stated that spouses reported stroke survivors' cognitive functioning as significantly worse than the survivors rated it themselves. Qualitative data analysis showed that there was an incongruence in ten out of thirteen couples with respect to the survivor's function in terms of their ability to make decisions, remain focused on a task, reassume household chores or engage in activities carried out prior to the stroke. This disparity was one of the core components for the stroke survivor's spouse's worry,

fear and sadness. Current service provision does not adequately address the range of needs that the stroke survivors and their partners require (Thompson & Ryan, 2009).

The current pilot study is novel in that it aims to contribute to the area in a number of important respects. Firstly, to investigate the disparity of views between both the partner of a stroke survivor and the stroke survivor on cognitive task performance. Based on previous empirical findings it is expected that that there will be a difference in the views within the dyad. In particular, this paper aims to seek answers to the following questions: Will the stroke survior or the partner rate the stroke survivor as worse across all cognitive domains? Secondly, as we are aiming to examine perceptions, a qualitative investigation was decided as an appropriate measure to explore common themes across the data sets and provided the groundwork for further research in the area.

MATERIAL AND METHOD

Ethical Standards: The authors assert that all procedures contributing to this work comply with the ethical standards set down by the Department of Psychology Ethics Board at Northumbria University.

Participants

Participants were recruited through Momentum Skills which is a brain injury rehabilitation centre, and also with the Stroke Association. Twelve stroke survivors (male = 8, mean age = 65.42. SD=12.31) completed the study; in which seven participants had suffered ischemic stroke, four had had a hemorrhage and one declined to report the cause of their stroke. Of those participants, five reported damage in the left hemisphere, and six reported right hemispherical damage. The average time since the stroke had occurred was 5.18 years (SD=5.94). Demographic information was also sought from the 12 matched partners (male = 4), of which, age ranged from 38-80 years (M=61.58 years, SD=13.23). The relationship between partner and stroke survivor was also recorded: nine pairs were married and three were cohabiting. There was an even split in carer status, with six reporting they were full time carers and six reporting that care was not required. The average length of time with the partner was 33.65 years (SD= 14.38). Ethical approval was gained from the School of Psychology and Sport Sciences Ethics Board at Northumbria University and all participants gave written informed consent.

Measures

Stroke Impact Scale

The Stroke Impact Scale (Duncan, et al., 1999) is a 59 item scale and this was utilized as it is designed to assess multidimensional stoke outcomes in 8

domains; strength, hand function, independence activities of daily living, mobility, communication, emotion, memory, thinking and participation. It has been deemed as a comprehensive measure of health outcomes for stroke populations (Duncan, Lai, Bode, & Perera, 2003) and shown to be valid, reliable and sensitive to change (Duncan, et al., 1999). This questionnaire has shown the internal consistency of Cronbach's alpha, 0.79 to 0.98.

Confidence Scales

To ensure that the investigation was looking at the stroke survivor and spouse's perception of survivor functioning, both the stroke survivor and their partner were asked to judge how well they believe the stroke survivor would do on each of the tasks presented. Responses were executed by presenting them both with a visual analogue scale based on Bond and Lader (1974), which was provided preceding the task occurring. The scale consisted of a 10cm line with 'Poor' and 'Excellent' anchored at either end, showing the minimal and maximal extremes of the relevant dimension to be measured: confidence in ability. Participants were also asked to provide a justification to their response on the visual analogue scale. This was performed by asking participants to complete another section under each of the lines asking them to justify why they gave this rating. Participants were asked to provide any evidence they deemed suitable to answer the question.

In-House Designed Picture and Verbal Memory Task

To investigate memory, an in-house program was designed to include a paradigm which probed semantic memory. The research procedure for this was developed and presented using the OpenSesame program (Mathôt, Schreij, & Theeuwes, 2012). As this was developed in-house, to establish normalised scores, a pilot study was conducted and the results of this are reported in the results section of this report..

Participants were presented with 15 images that were on screen for four seconds each. Photographs were selected on a basis of high-resolution conventional images; each image displayed a recognizable object or scene, such as a bridge, a cityscape or animals, similar as to those which would be taken on a camera. They were all made square, 700x700, to ensure that all pictures were standardised and not affected by orientation. The format of delayed matched to sample was used which has shown previous success in brain injury research (Müller & Knight, 2006; Hilary, Genova, Chiaravalloti, Rypma, & DeLuca, 2006). To record responses, participants were then presented with a booklet containing 45 images, a mixture of the 15 previously seen images and 30 novel stimuli. Participants were asked to circle the image they had previously seen and 1 point was scored for each item correctly identified; with a maximum score possible of 15 marks.

The second stage of the memory task focused on verbal recall. The methodology used a similar approach to that which has been used previously on stroke

survivors (Skidmore, et al., 2010; Pendlebury, Mariz, Bull, Mehta, & Rothwell, 2012). Words were randomly selected from The Psycholinguistics Database (Wilson, 1988) based on high imagery (scored as over 500) and words between 4 to 7 letters. In this two-fold procedure, participants were presented with 12 words which appeared on-screen for four seconds. After the words were seen, participants completed a free recall phase, in which they attempted to recall as many words as possible until they plateaued. Then, a second phase was conducted in which participants were presented with 12 new words. However, at the end of this phase, participants retained the words seen for 20 minutes. In this delay, participants carried out the rest of the procedure. Participants were given a free recall phase and then the recognition phase, in which the 12 words they had seen previously were arranged with 12 novel words. Participants were asked to tick the words they had seen previously. One point was scored for each word correctly recalled. All verbal memory sections were scored out of a maximum of 12 points.

Luria's Three-Step Test

As a measure of frontal lobe dysfunction, Luria's Three Step Test (Christenson, 1974) was completed. This task assesses motor skill by asking participants to move their hand in a set motion. The motion is a 'fist,' with the ball of the fist facing outwards, then 'edge,' where participants moved their hand in a cutting motion down onto the leg, and finally 'palm,' where participants place their palm down on their leg. Participants practiced using each hand first, before attempting to complete the rotation three times. This task has been frequently used on brain injured patients and shown to be a strong non-verbal measure of frontal lobe dysfunction (Weiner, Hynan, Rossetti, & Falkowski, 2011) For each completed rotation, a score of one was given, adding up to a maximum of six points.

Digit Span

Digit span was measured in order to assess the retrieval and manipulation of information in verbal working memory (Redick, et al. 2012). In the forward immediate recall span task the participant was presented with a short series of numbers and was asked to recall them back in the same order immediately after presentation. The procedure for the backwards recall was the same as that used in the forward span task, except the participant was required to recall the numbers in their reverse order. For both the forward and reverse digit span task, the testing began with three trials of 2-digit lists and if the participant successfully recalled the majority of trials at this level, then the digit span size was increased to 3-digits per set; again if the participant successfully recalled the majority of trials at this level then the digit span size was increased to 4-digits per set; and so on. When the participant failed in the majority of trials within a given digit span size then their forward/reverse score was the digit span below this threshold. The higher the score on the RDST the more proficient their EF was deemed to be. Forward and reverse digit span was scored independently as a maximum of 10 marks each.

National Adult Reading Test (NART)

The NART is a widely accepted measure of pre-morbid intelligence which is resistant to the effects of neurological and psychological disorders and has shown high split-half reliability, Cronbach's alpha .93 (Crawford, Besson, Parker, Sutherland, & Keen, 1987) and was therefore used here to assess general intellectual function. It requires participants to read aloud 50 words that are somewhat irregular in their grapheme-phoneme correspondences (Coltheart, Patterson, & Marshall, 1987). The responses were marked as correct or incorrect and scored at a maximum of 50.

Raven's Advanced Progressive Matrices

Raven's Advanced Progressive Matrices were utilised to investigate non-verbal pre-morbid intelligence (Penrose & Raven, 1936). Raven's Progressive Matrices are a set of multiple-choice items that require abstract reasoning to be solved. Each item on the test depicts a pattern that is obscure in its design, omitting one piece of the configuration. Participants were asked to choose which pattern they believe would best complete the design. For the purpose of this report, only the Advanced Progressive Matrices Set I was used (Raven, 1958). For this, there were 12 possible patterns to solve, which allowed for a quick yet accurate recording of non-verbal pre-morbid intelligence.

Procedure

The first part of the procedure included completing the Stroke Impact Scale. The partner was requested to complete the scale in the context of the stroke survivor, whilst the stroke survivor was asked to complete it in terms of their lived experience. The stroke survivor and their partner were then presented with the visual analogue scales to measure perceived confidence and the written report which were thoroughly explained. Once both parties felt comfortable completing the paperwork, instructions were given about each of the procedures verbally so that the partner was also made aware of the upcoming tasks. The participants were reminded that only the stroke survivor would be taking part in the tasks, and the partner should not allude to the answers. The tasks were presented in the following order; Picture Memory, Verbal Memory, Digit Span, Luria's Three Step Test, NART and Raven's Matrices. Participants were allowed as much time as they required in completing each task and constant encouragement was given by the researcher. The whole procedure took approximately 45 minutes to complete for each participant.

QUANTITATIVE RESULTS

Pilot of Memory Procedures

As the picture and verbal memory testing procedures were developed in-house, a pilot study was conducted to developed standardized variables to com-

pare when the full experiment was run. Eight participants (Male = 3 Female = 5) aged 22-27 (mean = 24.50, SD = 1.69) provided full consent to take part in the experiment. The testing procedure for this piece of research followed in-line with the research process used on the stroke survivors. Means and standard deviations are presented in Table 1.

Main Study

Stroke Impact Scale

All variables from participants were entered into the analysis for exploration and the means and standard deviations are presented in Table 2.

An independent-samples t-test was conducted on all variables to compare perception of survivor functioning from both the stroke survivor and the partner perspectives. There was a non-significant difference in the scores for stroke survivor or partner perception conditions across all dimensions of the Stroke Impact Scale, there were no systematic group differences between the partner and the stroke survivor on the perception of functioning (all $p>0.05$). However, it is worth noting that memory had a moderate Cohen's effect size value ($d = 0.48$) suggesting some further investigation was warranted.

As initial exploration showed no group differences, it was decided to split the data at a dyad level to investigate pair differences by using an independent sample t-test. This was done as the data implied that there were differences within the partnership. The data was split into the partner who scored the highest in the Stroke Impact Scale compared to the partner who scored the lowest regardless of their previous role. The data set continued with 12 high scoring partners and an equal number of low scoring partners. The means and standard deviations are presented in Table 3. Two dimensions were shown to be significant; mood and meaningful activities.

Table 1. Means (and standard deviations) of the results collected from the picture and verbal memory in-house design

Picture Memory	Verbal Memory Free Recall	Verbal Memory Free Recall - Delay	Verbal Memory Recognition - Delay
13.50 (1.85)	8.00 (3.20)	6.75 (3.85)	10.63 (1.69)

Table 2. Means (and standard deviations) of the results collected from the Stroke Impact Scale for stroke survivors and their partners

	Physical	Memory	Mood	Commu -nication	Activities	Mobile	Hand	Meaningful Activities	Recovery
Stroke Survivor	66.15 (29.73)	73.22 (29.59)	70.60 (23.04)	80.95 (17.18)	73.69 (27.12)	74.07 (21.85)	65.00 (40.40)	63.54 (23.09)	58.75 (21.55)
Partner	64.06 (28.84)	59.52 (27.97)	68.75 (16.54)	78.28 (16.64)	74.38 (27.84)	69.21 (25.64)	67.50 (39.57)	70.31 (23.63)	64.17 (23.14)

Table 3. Means (and standard deviations) of the results collected from the Stroke Impact Scale for stroke survivors and their partners divided into high and low scoring partners

	Physical	Memory	Mood	Commu -nication	Activities	Mobile	Hand	Meaningful Activities	Recovery
Stroke Survivor	66.15 (29.73)	73.22 (29.59)	70.60 (23.04)	80.95 (17.18)	73.69 (27.12)	74.07 (21.85)	65.00 (40.40)	63.54 (23.09)	58.75 (21.55)
Partner	64.06 (28.84)	59.52 (27.97)	68.75 (16.54)	78.28 (16.64)	74.38 (27.84)	69.21 (25.64)	67.50 (39.57)	70.31 (23.63)	64.17 (23.14)

There was a significant difference in the scores for the low scoring partner's perception of mood (M=60.42, SD=29.57) and the high scoring partner's perception (M=78.94, SD=18.48); (t (22) = 2.38, p = .027).

There was a significant difference in the scores for the low scoring partner's perception of meaningful activities (M=56.77, SD=23.87) and the high scoring partner's perception (M=77.09, SD=17.94); (t (22) = 2.36, p = .028).

This split was continued throughout the dataset, and as the previous measure was shown to be non-significant, only the significant implicit data was reported for the rest of this section.

In-House Memory Tasks – Verbal

An independent-samples t-test was conducted to compare the perception score for memory for words; the high scoring partner (M=57.00, SD=24.41) was compared against the low scoring partner (M=31.00, SD=23.72) and a significant difference was found; (t (22) = 2.65, p = .015).

In-House Memory Tasks – Picture

There was a significant difference in the scores given by the low scoring partner (M=41.83, SD=27.65) and the high scoring partner (M=68.17, SD=18.57); (t (22) = 2.76, p = .012).

Luria's Three Step Test

An independent-samples t-test was conducted to compare the motor perception score in the partner and the stroke survivor. There was a significant difference in the scores given by the low scoring partner (M=47.75, SD=24.81) and the high scoring partner (M=74.33, SD=17.75; (t (22) = 3.02, p = .006).

Digit Span

There was a significant difference in the scores given by the low scoring partner (M=28.67, SD=21.47) and the high scoring partner (M=53.42, SD=20.97); (t (22) = 2.86, p = .009).

National Adult Reading Task

There was a significant difference in the scores given by the low scoring partner (M=57.42, SD=14.41) and the high scoring partner (M=79.33, SD=20.90); (t (22) = 2.99, *p* = .007).

A Pearson product-moment correlation coefficient was computed to assess the relationship between the perception scores provided by the partner and stroke survivor and the raw score collected from the stroke survivor. The mean score of the reading task was 33.58 (SD = 12.35). In this task, it was found that partner's perception scores correlated with the raw score collected on the task (r = .82, n = 12, *p* = .001). It was also noted that in the dyad split, that both the high scoring partners, (r = .68, n = 12, *p* = .004) and the low scoring partners (r = .66, n = 12, *p* = .018) were able to positively correlate with the raw score on the task.

Ravens Advanced Progressive Matrices

There was a significant difference in the scores given by the low scoring partner (M=39.58, SD=22.38) and the high scoring partner (M=64.33, SD=24.29); (t (22) = 2.60, *p* = .017).

QUALITATIVE RESULTS

Using Braun and Clarke's (2006) steps for thematic analysis, firstly the researcher transcribed the data verbatim into Microsoft Excel using phrases provided by the stroke survivor and their partner. To develop wide emerging themes, data was not analysed at dyad-level and each code was used separately. This was then examined to check for errors. A thematic map was developed by first allocating initial codes within Excel which developed into themes, which were then narrowed down – when they were deemed similar – into a larger theme. This allowed for key concepts to be identified across the data sets. From this, it was determined that these themes were essential to understand both the scoring mechanism and the participants' beliefs about their abilities, the categories of which are as follows: "Confidence," "Insight into Ability," and "Post-Stroke Changes." Despite some overlap in participants' understandings of these categories, this should be viewed as a good interpretation of understandings which are relevant to each other as opposed to singular concepts.

Confidence

"[She'll] Probably do better than she thinks but keeps putting herself down"
Participant 3, Partner

Confidence was defined as the participants' feeling or belief in their capacity to complete the task provided to them, which also included their apprehension about the task itself. Often, confidence was heavily linked to their self-confidence, their belief in themselves, which was shown to be an array of both positive and

negative statements. Confidence was highly associated with self-efficacy, the belief in their capacity to fulfil behaviours which produce specific performance attainments (Bandura, 1997).

"Have a problem with words – we'll see"
Participant 8, Stroke Survivor

Confidence and, subsequently, self-efficacy have been shown to play a vital role in the rehabilitation and recovery of the stroke survivor (see Jones & Riazi, 2011, for a full review). Disappointment with progress has been shown by Gainotti and Marra (2002) as a subsidiary element to the prevalent negative psycho-social sequelae experienced by the stroke survivor. Understanding individual perceptions of confidence have been discussed as a key element of working towards goals. These goals may be able to help support practitioners, and potentially partners, understand the difference responses to rehabilitation (Jones, Reid, & Partridge, 2008). Current measures put in place by practitioners often utilise functional performance. Whilst deemed essential as a measurement tool of progress, it does not reveal perceived confidence about ability and whether or not the stroke survivor feels confident to continue at a particular level once discharged (Jones, 2006).

In overall rehabilitation research of other chronic conditions, Barry, Guo, Kerns, Duong and Carrington-Reid (2003) showed that high levels of self-efficacy are associated with good mood, high reported quality of life and functional independence. In the context of a stroke, research conducted by Robinson-Smith (2000) showed that self-efficacy is a construct which correlates strongly with an individual's quality of life and depressive state (Shan, Chang, Chau, & Gardner, 2014; Schmid, et al., 2012).

Participants often made comments which were linked with negative self-confidence, implying that the result that may be presented would be poor. They claimed that they were *"not very good"* (Participant 5, Stroke Survivor) or that the stroke survivor was *"not very good with numbers"* (Participant 5, Partner). However, not all commentary was negative, and both stroke survivors and their partners often displayed positive confidence: *"should be good – logical mind"* (Participant 4, Partner). This display of positive commentary was still prevalent within the data and therefore should be considered a crucial part to the development of confidence.

Insight into Ability

"She's got 5 thumbs and 2 left hands"
Participant 11, Partner

Insight into ability was defined as participant's awareness of their capabilities, acknowledging their debilitated cognitive processes but also skills which they consider to be undamaged by the stroke. It also included adaptations made by the stroke survivor to support alterations caused by the stroke.

"Ok with [right-hand side] – very little movement in [left-hand side]"
Participant 6, Partner

Humans are only moderately proficient at self-evaluation, especially when we are requested to report on a broad topic (see Zell & Krizan, 2014, for a full review). Brain injured patients have shown a warped perception of their ability to complete tasks, as discussed by Prigatano (2005) who noted that, regardless of the time period after a head injury, traumatic brain injury patients showed deficits in self-representation in both semantic and episodic memory. Furthermore, those who have had a traumatic brain injury show a high level of insight and had greater levels of motivation. However, they also displayed increased levels of emotional distress, yet their outcomes did not differ from those with low self-awareness (Fleming, Strong, & Roderick, 1998).

"Shouldn't be difficult – problems with finer motor skills"
Participant 4, Partner

Therapy to aid the rehabilitation process has been suggested which includes improving self-awareness. It has been suggested that the client should conduct practical exercises to help ground their knowledge on their ability (Ownsworth, Turpin, Andrew, & Fleming, 2008). Unawareness of illness might impede stroke survivors from recognising their disability, meaning that they partake in potentially risky activities (Heilman, Barrett, & Adair, 1998). This has been shown by exploration into limb ownership, in which some patients observe a disturbed sensation in their limbs where they believe they can function normally, where there is evidence to prove this is not the case (Karnath & Baier, 2010). There is a wealth of literature which discusses anosognosia. However, as the quotes given by participants did not heavily discuss motor impediments, it will not be discussed as part of this research (see Orfei et al, 2007, for a full review of the literature).

There is a dearth of literature which looks into the self-awareness of the cognitive abilities of stroke survivors. Whilst this can be applied to the cognitive function, this can only be done so tentatively, as it still needs to be backed-up with empirical evidence. Participants in the current study frequently discussed their inability to complete a task successfully, as they did not believe they had the relevant skills to complete it, "*memory poor*" (Participant 9, Stroke Survivor).

Post-Stroke Changes

"Numbers were his bread and butter"
Participant 4, Partner

This theme was defined as changes which were reported by either the partner or the stroke survivor that had altered after the stroke. This encompassed cog-

nitive changes that had noticeably altered, discussing their previous positive status on a cognitive ability, and its subsequent deterioration.

> *"Didn't read for 4 years after stroke, was a big reader of 2+ books per week, has started reading in last 12 months cycling mags in which he's interested"*
> Participant 8, Partner

Cognitive impairment after stroke is commonplace (Narushima, Chan, Kosier, & Robinson, 2003) and vascular cognitive impairment has been shown to play a major role in life after a stroke. Thomson et al (2009) noted both these cognitive and interpersonal changes which occurred after a stroke remain a key aspect of recovery.

This was a small theme, with most codes developed from the partner of the stroke survivor. Often, they compared their partner to the previous state or reported on functions which had remained constant pre and post stroke.

DISCUSSION

The current pilot study aimed to extend our understanding of the impact of a stroke by investigating the perceptions of survivor functioning from both the partner and the stroke survivor's points of view and provide the groundwork for future work in this area. Stroke participants took part in a battery of cognitive tasks which investigated global cognitive function. In particular, this paper aimed to investigate the following question: Will the stroke survior or the partner rate the stroke survivor as worse across all cognitive domains?

It was predicted that there would be a difference between the stroke survivor and their partner on their scores on the judgement scales. Initial analyses implied that there were no systematic group differences, eliciting no significant results between the partner and the stroke survivor on either the Stroke Impact Scale or the judgement scales. However, further exploration into the data showed that there were differences in the ratings, but as the direction of these was non-consequential more investigation was needed. This was further encouraged by the moderate Cohen's D value regarding memory ($d = 0.48$).

In the second set of analyses when the dyad was divided up to high- and low-scoring partners, it was shown that for all tasks there were significant differences on the confidence score. Further, the Stroke Impact Scale showed that both mood and ability to take part in meaningful activities was also significant and overall recovery ($p = .06$, $d=.73$), was approaching significance. Whilst there was no set direction that the data was heading, there was still a difference within the dyad.

The second aim of the study was to assess the relationship between the confidence scores provided and the raw score shown by the stroke survivor. In all cases bar reading, the results did not correlate the raw score of the stroke survivors. In regards to the insignificant correlations, all groups of participants reported confidence that was either an over- or under- estimation of the actual

ability shown by the stroke survivor. Reading, however, was shown to be the only successful prediction, with the partners being able to provide confidence scores that showed a positive relationship with the raw scores collected. This was further enhanced when using the dyad split, which showed that both groups, the low and high scoring, were able to provide confidence scores that correlated with the raw scores. One of the potential reasons is that the National Adult Reading Task is somewhat familiar compared to the rest of the test battery. It is a sensitive measure of prior acquaintance with words, as reading is considered a heavily practiced ability that, once established, can be maintained despite deterioration in other areas of cognitive functioning (Nelson, 1982). Therefore, the participant's ability to provide confidence scores which are related to their raw score may be much more likely if the task is recognizable (Pachalska et al. 2015).

Whilst the quantitative scores allowed the research to probe the differences in perceptions, these results are further bolstered by the qualitative data collected from the participants. As aforementioned, partners' and stroke survivors' confidence scores showed little relationship with the raw scores collected from the stroke survivor. However, these results relate to the qualitative data collected, which show three major themes: "Insight into Ability," "Confidence" and "Post Stroke Changes." Most of the "Insight into Ability" theme showed negative connotations, remarking themselves as unable to complete a task and acknowledging debilitated cognitive processes. As discussed previously by Prigatano (2005), those with a brain injury report themselves as worse in both semantic and episodic memory than those without a brain injury (see also: Pąchalska et al. 2015). This poor self-representation means that participants are unable to accurately portray themselves, and, consequently, cannot predict how well they will do on tasks.

The results of the digit span task exemplified this; although most of the stroke patients rated their inability to complete the task, nearly all succeeded at the task, with some participants even being able to recall up to nine digits. Furthermore, these scores can also interplay with survivors' confidence and self-efficacy. Participants regularly doubt their abilities, which have been shown in the low judgement scores fund in the present study – however, many of the scores presented are within acceptable ranges. Therefore, it may be useful, within the rehabilitation process, to give stroke survivors regular testing to ensure that they have full awareness of their ability, which may improve the rehabilitation process (Shan, Chang, Chau, & Gardner, 2014).

However, as the current study also incorporated the partner of the stroke patient, it is important to discuss their results. There is emergent literature that has shown that the partner frequently rates the stroke survivor as less capable than themselves (Thompson & Ryan, 2009; McCarthy & Lyons, 2015; Barker & Brauer, 2005; Quinn, Murray, & Malone, 2013). However, this was not the case in the current study. This study was able to show that there is a pair difference between the stroke survivor and their partner, but not a systematic group difference, meaning that the partner did not regularly rate the stroke survivor as less capable, or vice versa. This conflicts with many pieces of research which imply otherwise,

stating that the disparity within the view of the partner is a regular occurrence, and is seen throughout the literature on a variety of different illnesses (Lobchuk & Degner, 2002; Lyons, Stewart, Archbold, & Carter, 2009; Sterba, et al., 2008; Benyamini, Medalion, & Garfinkel, 2007).

Existing literature which discusses incongruence mostly focuses on the implications of the incongruence for the patient, or examines the effect of discrepancy by only investigating spousal perceptions (Cecil, et al., 2010; Jubber, 2008; Andrén & Elmståhl, 2005; O'Callaghan, McAllister, & Wilson, 2011). Garand et al (2007) provided evidence that behaviours presented by the affected person which were unfamiliar can cause unnecessary strain and subsequently degrade marriage quality. The current study is somewhat unique in the respect that it incorporates both the stroke survivor's and the partner's perceptions of survivor functioning to help add to the body of literature on spousal caregiver mental health.

This incongruence which was found in this piece of research, whilst conflicting with other studies, still adds weight to the argument that rehabilitation practices must involve the partner more intensively. This disconnect can have a massive impact on an informal caregiver's mental health (McCarthy & Lyons, 2015). Current research findings suggest that greater attention needs to be brought to the importance of helping the patient and their partner recognize these differences in their perceptions, which helps to alleviate stress (Ezer, Rigol Chachamovich, & Chachamovich, 2010). Research conducted by Kauhanen et al (2000) showed that married stroke survivors do not cope as well with their impairments compared to unmarried stroke survivors, yet research into other brain injuries have shown that a good quality relationship can buffer the effects of the negative consequences caused by informal caregiving (Quinn, Clare, & Woods, 2009). However, it must be ensured that strong relationship bonds do not increase caregiver worry, as research conducted by Lyons, Stewart, Archbold and Carter (2009) noted that wives who care for their partners experience a higher level of role strain compared to husbands who do the same duty. Tension that develops from incongruent estimations of everyday functioning may reinforce concern, placing the caregiver at risk of poorer mental health.

The strengths of this study include its focus on both perceptions of stroke survivor's abilities and their actual performance. The mixed methodology enables one to look at this from both quantitative and qualitative standpoints and the fact that the study incorporates both the stroke survivor's and the partner's perceptions of survivor functioning enhances the uniqueness of the study.

CONCLUSIONS

The findings from this study not only have implications for stroke survivors, but may also raise similar issues in patient groups living with other debilitating conditions. This study highlights the needs for more interventions placed at the level of the dyad which has already seen crucial success by Bakas et al (2009). When giving partners more information about a stroke, they were able to bring

round a more positive and optimistic outcome, to help them cope with the changes seen in the stroke survivor. If health care professionals are able to acknowledge that there is a disparity in the awareness of ability between the patient and the partner, then care can become more integrated with these perspectives and it can recognize the consequences for the couple. This means that rehabilitation should encourage communication between the patient and the partner, helping to give both of them realistic expectations of the recovery process. Consequently, this approach should help increase optimism, reduce worry and other negative feelings that participants may feel. By integrating these models, it is hoped that we may foster a more positive relationship and help reduce incongruence and relationship strain.

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