

Research Space

Journal article

How is carer strain related to the recovery of stroke survivors with right hemisphere dysfunction? Implications for practice
Stein, M. and Reynolds, F. A.

“This is an Accepted Manuscript of an article published by Taylor & Francis in Disability and Rehabilitation on 16th June 2020, available online:

<https://www.tandfonline.com/doi/full/10.1080/09638288.2020.1775311>”

How is carer strain related to the recovery of stroke survivors with right hemisphere dysfunction? Implications for practice

Abstract

Aim: Right hemisphere strokes are associated with neuro-behavioural impairments including hemi-inattention, impulsiveness and anosognosia, which can impede stroke recovery and adversely affect carer health. This study explored the impact of associated impairments on carer strain and depression through a mixed methods approach.

Method: Fifty-one carer-survivor dyads were recruited from inpatient rehabilitation units and followed-up for six months. Validated measures assessed survivors' physical and cognitive function and carers' strain and depression levels. Survey methods captured qualitative experiences of the caring role. Data collection occurred at baseline, discharge, six weeks post-discharge and six months. Multilevel-modelling and thematic data analysis, were employed.

Results: Carer strain median scores were within normal ranges of the Caregiver Strain Index scale. Carer strain was positively linked to carer depression, number of carers' concerns reported and survivors' anosognosia levels. Carer strain was negatively linked to the survivors' functional and cognitive abilities. Carers' experiences differed qualitatively with caring concerns increasing over time.

Conclusion: Carer strain worsens with increases in significant concerns about the rehabilitation process and poor survivor functioning skills, which potentially increase risk of depression in carers. Consequently, improving right-hemisphere stroke survivors' recovery and nurturing the carer-survivor relationship are likely to enhance overall outcomes and caring experiences.

Key words: stroke, caregivers, strain, cognition, depression, empathy

Introduction

In England, approximately 110,000 people have a stroke every year [1], of whom the majority survive the event and return home after in-patient rehabilitation. More than half of survivors depend on support from spouses and family members with everyday activities and emotional health concerns [2]. Whilst some informal carers report satisfaction and fulfilment with their role, others continue to report significant challenges, unmet needs and dissatisfaction associated with their role (3,4). Carers have described their lives as ‘turned upside-down’, regretting the lack of information and support to assist the adjustment process [5].

Caregiver ‘strain’ and caregiver ‘burden’ are often used interchangeably in the literature [6,7]. Both terms encompass the experiences of carers when ‘the demands of care outweigh available resources’ leading to physical or emotional ill-health [7]. Objectively, carers’ own time use and preferred occupations may be eroded both by the time spent helping the survivor, and through increased involvement in household tasks. Subjective aspects include distress, frustration, uncertainty about the future and marital dissatisfaction or disharmony [5,6,8].

Health and social care professionals play a key role in promoting the survivor’s recovery [9] and supporting informal carers in order to reduce carer burden and improve their quality of life [10]. Therefore, understanding the complex relationship between extent of survivor’s stroke recovery and carer-associated strain across the care pathway is of fundamental importance in designing and promoting evidence-based and client-centred practice; especially the efficient deployment of specialised resources to carers who can use them effectively.

There have been studies into the impact on carers of stroke survivors with aphasia (typically a consequence of left hemisphere stroke) [11-13] but the challenges of giving informal care to people specifically affected by RHS have been relatively neglected.

Literature review

Carers of stroke survivors tend to report more strain and /or depression when their loved ones have greater levels of impairment, physical dependency, cognitive dysfunction, and behavioural problems in the early months post-stroke [6,14]. Female carers seem more adversely affected than males [6]. Positive resources have protective effects, with carers reporting better health, experiences of control and appropriate social support, tending to experience less strain and depression [2]. However, how carer resources change (develop or deplete) over time for different caring situations and stroke impairment profiles is not well known [15].

A considerable body of research into carer strain has been undertaken on carers of survivors with generic stroke profiles treated as one undifferentiated group [15,16]. However, stroke is heterogeneous with respect to severity and type of impairments. It has highly variable consequences for both survivor and carer. **Whilst some caring experiences such as increased anxiety and doubt about ability to care are common following all types of stroke, other experiences may vary according to the type, hemispheric localisation and severity of stroke impairments. In this respect, generic data makes it difficult to attribute results to specific stroke-carer subgroups.**

For instance, left hemisphere stroke (LHS) is predominantly associated with motor and speech and language difficulties. Right hemisphere stroke (RHS) dysfunction is associated with subtle cognitive impairments including anosognosia (denial and reduced awareness of stroke deficits), hemi-inattention, emotional dysregulation and impulsiveness, impaired

judgement and decision-making [17-19]. Whilst any of these deficits can adversely affect independence levels within activities of daily living (ADL), it is clear that their impact on social communication, participation and relationships with significant others is quite different [17-19]. Consequently it can be argued that different hemispheric impairment profiles may benefit from different approaches to addressing challenges faced by carers such as, preparation and training for their role. This argument is further supported by research findings from studies documenting the impact of caring for stroke survivors with aphasia (typically a consequence of LHS) [11-13,20,21]. Carers of spouses affected by aphasia tend to report higher levels of distress and depression, role adjustment and social isolation, reflecting communication barriers and reduced marital satisfaction [2,21] compared to their counterparts without aphasia.

Studies on the needs of carers of RHS survivors are relatively rare. An isolated study by [22] suggested that carers of RHS survivors may have specific educational, training and support needs in connection with their role, However it is not clear what these needs are and how to potentially address them. The study has methodologically limitations including a cross-sectional design and lack of carer focused outcomes measures. The research study reported here attempts to address the gap identified in the literature. In doing so, it overcomes important methodological limitations by employing mixed data collection methods designed to answer the following research questions. The focus was on the first 6 months post-stroke:

1. How do carer burden and depression levels change in RHS conditions?
2. How is carer strain related to functional recovery of RHS survivors?
3. What are the caring experiences and concerns associated with caring for RHS stroke survivors?

Materials and Methods

Participants

The researcher (an Occupational therapist) identified and approached potential participants from admission records on the stroke rehabilitation units and by speaking to the stroke survivors and family when present. Eligible carer-survivor dyads received a verbal explanation of the study by the researcher who also answered any questions in the process. Participation was voluntary; participants could opt out of the study any time without giving an explanation. In addition, they were given a participant information sheet with details of the study, the researcher's contact information and separate consent forms for the survivor and the carer. They were asked to decide within two weeks whether they wanted to participate as a dyad.

All participants gave written consent prior to enrolment. Recruitment occurred over an 18-month period from two stroke units in the south of England.

Inclusion criteria: Stroke survivors with first or recurrent RHS confirmed by radio-imaging techniques, capable of giving written informed consent and had an identified informal carer at admission to the stroke unit. Carer was defined as a family member or close friend who was in reasonably good health (determined from observation and initial interview by the researcher) and was not formally paid for their support.

Exclusion criteria: stroke survivors living in residential homes prior to stroke and stroke survivor-carer dyads whose command of the English language was insufficient to engage with the research assessment protocol. The first author, a trained researcher Occupational Therapist, supported by the multidisciplinary stroke in-patient and community teams recruited, assessed and collected all the data from participants but was not involved in patient treatment.

Design

A serial (longitudinal) design allowed for appropriate follow-up of the carer-survivor dyads during the first six months after stroke and collection of sufficient data to explore important relationships among factors researched in this study. All stroke survivor-carers dyads were formally assessed with the research protocol (described below) - at admission (T0) to, and discharge (T1) from, the stroke unit, 6 weeks post-discharge (T2) and 6 months since stroke (T3). The assessment window was up to 7 days for the survivor and 14 days for the carer.

Demographic data for survivor (age, gender, stroke severity (as measured by the National Institute of Health Stroke Scale [23]) and duration of stroke unit rehabilitation); details were extracted once from the medical records. Carer demographics (age bracket, gender, social status, work and existing caring commitments, previous caring experience) data extracted from demographic section in baseline carer survey. Community follow-up visits were undertaken by the researcher to collect survivor and carer data.

Research protocol

The protocol consisted of a test battery for the survivors and strain and depression measures for the carers. Table 1 contains a brief description of each test [23-31] no specific test order was followed.

Insert near here

Table 1 Description of carer and survivor measures employed in the study

Carer surveys – In addition, carers also provided written information in the form of a semi-structured questionnaire at all time-points (T0 to T3). Carers could complete this task during visits (hospital or home) or by post - a pre-paid research addressed envelope was available. The survey included demographic details and background information at baseline (T0) - age, gender, relationship to survivor, social situation, nature of work and other existing caring commitments, past caring experiences and type of community accommodation. At follow-up (T1, T2 and T3) the carers were prompted to check that demographic and background

information was still correct and invited to comment on their caring experience via open-ended questions. They were prompted to comment on ease and extent of communication with the survivor, any behavioural/relational/health issues encountered and if so, how they were managed, any education and training, or other support received in relation to their caring role, and any other specific concerns arising from their caring role and responsibilities.

Data Analysis

Quantitative data processing and management were handled by statistical software package SPSS version 20 [32] and modelling by MLwin 3.01 [33]. Multilevel modelling (MLM) is suited for the analysis of highly dependent and variable data [34]. In statistical terminology, high dependency refers to data obtained from two or more variables that are inherently related e.g. in stroke recovery, changes in motor skills are somewhat dependent on changes in cognitive skills which are also dependent on changes in memory, perception and executive function. Significant variation refers to substantial differences that may exist within and between stroke survivors, even though they all have the same health condition i.e. no one stroke profile and experience is quite the same as another.

In the current data set, use of MLM is supported by an intra correlation coefficient of 0.6, which indicates significant variation across individual participant carers and survivors. MLM affords other important advantages over ordinary regression analysis used in past studies [22,35]. These include handling of missing data which potentially can bias results unless properly accounted for during modelling [36,37]. Both stability of coefficients and accuracy are important for this study for accurate interpretation and generalisation of the results to a wider RH stroke population. In addition 'time since stroke' was explicitly modelled as an independent factor so that, its contribution to carer strain could be directly estimated from the models [36]. If necessary, more information on the modelling method is available from the first author.

A two-level random coefficient model was constructed, conventionally level one contained serial measurements (expected to change over time) and level two contained participant characteristics (not expected to change appreciably over time) [34]. In all the MLM models, the dependent variable (DV) was carer strain (CSI scores). Time since stroke was modelled as an independent variable (IV) together with 1 - 2 potential explanatory variables included in the design (stroke severity, overall functional ability, cognitive function, anosognosia, balance skills, self-efficacy, survivor age, carer gender, carer age and number of concerns). All the factors are clinically relevant and associated with RHS in the reviewed literature [17-19,22,38-40]. All variables were mean centred to reduce multicollinearity and aid interpretation of regression coefficient estimates [41]. Significance level (alpha) was set at 0.05 with 95% confidence intervals.

Qualitative data in the carer survey were thematically analysed using a framework and matrix method described by Gale and colleagues [42]. Two researchers read written responses and summarised the data for each carer. During this process, key concerns and caring experiences relevant to the study, were abstracted and numerically coded. In the second round, the codes were grouped into categories and themes. The number of concerns per carer was totalled so that, it could be modelled with other factors evaluated in the study. Specific comments and findings from the qualitative analysis aided the interpretation of findings from quantitative results. Local university and Research Ethics Committees approved the study (08/H1102/6).

Results

In total, 77 dyads were eligible, but 26 carers declined participation either because they were in shock from the sudden impact of stroke on their loved ones or due to family/work commitments. The remaining 51 dyads formed the sample.

Insert near here

Table 2 Demographic details for 51 carer-survivor dyads

Table 2 contains participants' demographic profiles. The majority (38) of carers were female and over 50, 12 were older than 75 years old. Out of 51 carers, 36 were partners or spouses, the rest were offspring. In comparison, 45% of survivors were male, mean age of 75.8 (range 46 to 92) and tended to have moderate (21) or severe (29) strokes as measured by the National Institute of Health Stroke Scale (NIHSS) [23]. The duration of in-patient rehabilitation was approximately 30 days although there was considerable variation from 5 to 86 days. The majority of survivors (39) were discharged home (33) supported by living-in carers and six by informal carers who did not live-in), and 12 were discharged to residential institutions.

Quantitative results

Table 3 shows a detailed breakdown of the quantitative results obtained for all participants for the duration of the study.

Insert near here

Table 3 Descriptive statistics for all participants at baseline and follow-up assessment time-points, median (upper, lower quartile) scores and percentage proportions

As expected, the attrition rate was highest at community follow-up points (T2 – T3). This amounted to 6.3% of observations missing across all quantitative measures. Reasons for attrition were discontinuation with the study due to the survivors' deteriorated health and associated carer stress, two survivors passed away at T2-T3, and difficulty contacting carers to set up appointments for the community phase of the study.

For the first six month post stroke, overall carers' strain levels tended to remain relatively stable (median score = 3.5 to 5) and well within normal range of CSI (0 to 6). However, inspection of individual CSI records for 43 carers between admission and 6 months post

stroke showed a tendency for (i) reduction of 2 to 3 CSI scores for 13 carers (ii) increase of 2 to 3 CSI scores for 12 carers and variable pattern for 5 carers. In addition, a quarter of the CSI scores were 7 or higher at discharge indicating abnormally high levels of strain experienced by some carers at this point in time.

Depression levels tended to remain within normal (0 to 4) or very mild (5 to 8) at most as measured by the GDS scale. The number of concerns reported by carers increased from 183 to 218 at discharge and six weeks post but then dipped at 6 months to 174.

Overall, stroke survivors' levels of functioning, postural control, cognitive function and self-efficacy skills improved with time as indicated by changes in the EBI, PASS, MEAMS and GSE median scores respectively. However, the upper and lower quartile scores at either end of the respective scales indicate considerable variation within the sample on each measure. Frequency of continence dysfunction, anosognosia and abnormal hemi-inattention levels tended to reduce with time after stroke but were still present in substantial amounts six months later.

MLM results

The results supported a negative relationship between carer strain (DV) and stroke survivors' overall functional ability when adjusted for the effects of time and survivor differences in age and gender ($p=0.0001$, CI -0.052, -0.024). However when cognitive ability was introduced in the same model, functional ability tended to become statistically insignificant ($p=0.12$, CI -0.041, 0.014) compared to cognitive ability ($p=0.004$, CI -0.23, -0.04).

A positive relationship was identified between carer strain and carer depression ($p<.0001$, CI 0.73, 1.55), and between carer strain and survivor anosognosia level ($p<.0001$, CI 0.46, 1.97), when adjusted for effects of HI (neglect) status, differences in stroke severity and time. A

positive relationship was identified between carer strain and number of carer concerns ($p=0.0028$, CI 0.043, 0.29) when adjusted for carer depression, survivor age and time.

Qualitative results

Survey completion rates varied at each assessment point - 51, 28, 26 and 21 at T0, T1, T2 and T3 respectively. Twenty-one (41%) of carers returned all four completed surveys, all the data available were included in the analysis. Descriptive analysis showed that 18/51 carers were in paid employment up to stroke onset compared to 5/28, 4/26 and 5/21 at discharge, 6 weeks post and 6 months after stroke. Carer comments indicated that they found it difficult to juggle paid work and a demanding caring role. Regarding previous caring experience, 17 (33.3%) were new to the role, 32 (62.7%) had some experience and two were supporting another individual besides the stroke survivor.

Following is an in-depth analysis of the qualitative data. Data integrity confirmed by triangulation from other data sources about carers (including demographic and quantitative data) and from two researchers who had a clear audit trail and processes in place for data coding and agreed negotiation.

Insert near here

Table 4 Breakdown of carer concerns grouped by theme, category and time post stroke

With reference to themes and categories (shown in brackets) in Table 4, a significant proportion of carers reported “disbelief” (carer 23) regarding “how little” (carer 25) the survivor could do for themselves soon after the stroke and after discharge from in-patient care (2c) (e.g. carers 1, 7, 34, 40).

Some reported high anxiety and stress levels that disturbed their daily routines during the first 2-4 weeks as a direct result of the stroke (1a) (e.g. carers 1, 23, 34, 40, 44). Further,

whilst meeting with professionals involved in the stroke survivor care alleviated some of the anxiety, they reported difficulty trying to meet with professionals post discharge (1h) (carers 1, 10, 38). Although questions regarding their own health, wishes and perceived ability/time to care were not directly requested, nine carers (e.g. 3, 4, 12) forwarded the information themselves (1a, 1f, 1j).

At discharge point, 15 carers felt able to care for the survivor at home with support from community services (e.g. carers 10, 21, 24). Ten felt that the survivors were still making progress in therapy and should stay longer on the stroke unit “Mother is not far from walking – why is she being discharged? Will she get more rehab?” (carer 22). Eight expressed relief that the survivor was going to institutional care. However they felt guilt about not being able to support the survivor at home (1c, 1e, 1g) “Don’t feel good about that but was unable to care for him at home because I am not well myself and he needed more assistance than I could offer” (carer 7, supported by comments from carers 1,16,39).

Some carers reported that their needs were assessed for the first time after discharge due to unforeseen circumstances such as feeling overwhelmed by the demands of the caring role (carers 5, 10, 25). Examples included regular checks on the survivor that they were not in danger of falling (carer 5), that they did not need anything and were safely sitting in the chair (carer 10) (1a, 1j). Others were coping with difficulty, they were upset that they could not be of more help to the survivor (carer 25) (1c, 1d). Some carers reported coping with the demands but were left on their own to problem solve and did not necessarily know how or whether they were doing “the right thing” (carer 5) (1e). This general lack of uncertainty and taking on a new caring role was perceived as cause for high anxiety levels, emotional upsets, fatigue, and difficulty getting “anything much done during the day” (carer 10) (1j). There was a sense of anger directed at professionals because “they should have known better” (carer 21)

Carer Strain and Right hemisphere dysfunction

and “my needs, my situation was not considered in this whole process, only what the survivor wanted” (carer 7) (1a, 1b, 1c, 1e, 1g, 1j, 1k).

Carers tended to report less anxiety around coping with their role at 6 months after stroke, they appeared to be coming to terms with the reality of the situation as they realised the full extent of the commitments (1c, 1i, 1j). This was indicated by statements like, “He is unlikely to get much better” (carer 23). “I feel very trapped in the situation” (carer 21). “Returning to work is out of the question” (carer 9). “I cannot do anything on the spur of the moment - simply going out for walks or swimming because everything needs to be so carefully planned” (carer 29). Most had given up other volunteering roles (1k).

Specific carer reported concerns in relation to stroke-related disability

The majority of carers identified challenging behaviour of the stroke survivor as the most problematic and worrying concern (2b). They believed that deteriorating cognitive ability, mental and/or physical survivor health were important underlying factors for the observed behavioural changes in the survivor (2c). “He is very forgetful and nothing what he was like before, he does not see the real picture that he needs somebody here to support him” (carer 25). The carers felt that they lacked appropriate skills to communicate and relate to the survivor who was perceived to be, “too demanding” (carer 25), “difficult to reason with” (carer 34), “angry and forgetful” (carer 20) and “in denial of his/her abilities” (carer 31) (2b, 2c). There was a sense of this problem needs fixing and a perception that their skills were severely lacking in this area (1e, 1g). From the comments, the carers believed that more and earlier education, training, counselling were needed in order to remediate and support both carer and survivor in the community (1c, 1g, 1h), supported by “I have hardly any medical background” (carer 21) and “How to improve sensation in the hand?” (carer 8) and “His mental state of mind – how is he to be supported to adapt to this huge life change?” (carer 12). Most indicated that they took life “day by day” (carer 29) and that this loss of control

over their life routines and occupations had taken a toll on their health and that of their family. These sentiments were also echoed (albeit to a lesser extent) by the carers/family who regularly visited RHS survivors discharged to care homes.

Discussion

This is the first serial study to explore in some depth the relationship between carer strain and RHS dysfunction in the first six months. It employed mixed methods approach to data collection and analysis using multilevel modelling to model serial data and thematic analysis to help explain context-specific experiences. All these factors lend credibility to the results.

The main finding was that change in overall functional ability of RHS survivors had important effects on carer strain levels even when survivors' age and gender are considered. In support of this statement, improvements in carer strain levels (amelioration) were best explained by improvement in overall functional abilities of the survivors and a reduction in anosognosia levels. Perhaps this is reflected by a reduction in the number of caring concerns reported and lower depression levels.

Sample representation

Sample size was modest (51 dyads) given the nature of this study and attrition was relatively low (15%) compared to other carer studies which report up to 56% data loss [43]. It is possible that the recruitment and data collection methods used helped with retention of participants, especially giving up to two weeks to decide whether to participate and organised community follow-up visits by the researcher to collect serial data instead of telephone assessments. This method is more resource intensive and costly however, it was an important source of contact with the participants in the community phase of the research.

The main threat to representation of the sample came from 26 carers who declined to participate for understandable reasons, mainly feeling overwhelmed and shocked by the sudden impact of stroke on their loved ones, family and/or work commitments. Whilst this is

to be expected - the proportion of carers declining participation is relatively high - it may have implications to generalization of findings. There are also financial and practical implications to early carer recruitment for future studies; in that a longer duration may be needed to recruit a reasonable sample size and preferably multiple stroke units to increase access to potential participants.

Based on sample demographics, the findings from this study are more applicable to female carers aged 50 to 80 years, who care for older RHS survivors (average 75 years) recovering from moderate and severe RHS strokes, as measured by the NIHSS. Most carers were spouses; they were more likely to participate than offspring who often had family and/or work commitments to juggle along with the caring role.

Whether the type of carer relationship (e.g. spouse/offspring) with the survivor is important is difficult to know with certainty. However, carer comments suggest that spouses and offspring cope differently with differing aspects of caring. Spouses appeared to find it harder to cope emotionally and experienced more strain when role reversal was involved, possibly due to change in power dynamics and intimacy of the relationship. Spouses appeared to be more guilt-induced than offspring when the survivor did not return home. Offspring seemed to accept and rationalise discharge to an institution more easily than spouses. Spouses appeared to find it harder to adjust and cope when there were significant personality and behaviour changes associated with RHS e.g. unrealistic expectations, denial of stroke impairments, impulsiveness, anger and poor decision-making. Carer comments especially spousal suggest that they lack resources to cope with challenging situations – not just educational but also practical – as they unfold e.g. to defuse anger or cope with the aftermath of anger directed at the carer.

Future research could be directed at understanding the importance of the type of carer relationship with the RHS survivor and how best to address the psychosocial issues arising at

different stages of recovery. This may help the carer-survivor unit to function as “one being” rather than simply existing in the community.

Relationship of carer strain and depression levels

The majority (86%) of carers were between 50 and 80 years old, female and not clinically depressed. However, at 6 months follow-up, a quartile of GDS scores were 6.3 or higher. This suggests that some carers were clinically depressed at this stage although this is difficult to determine without looking at individual cases. Nevertheless, depression may have contributed to carer strain levels in a relatively small proportion of carers. In this study, carer depression was an important positive predictor of carer strain. It should be included in future research designs aimed at evaluating contributory factors to carer strain. The stroke survivors in the sample tended to depend substantially on carer assistance as indicated by carer reports in the surveys and supported by low levels of independence (low EBI scores) and high rates of continence dysfunction (refer to table 3 for details). Survivor features are contextually important and should be taken into account when interpreting the results. Following is a discussion on other important relationships identified in the data.

Relationship of carer strain and change in the survivors' overall functional ability

MLM results from the current study corroborate those from past studies [22,44] in that higher survivor function early on after stroke predicts lower carer strain levels - even when different carer and survivor measurement tools were used in the current and past studies [22,44]. Although this lends credibility to the results obtained, further comparison is limited by important differences in research design including sample representation (RHS versus generic stroke dysfunction), differences in neurological severity at baseline and time elapsed to first measurements and different statistical models.

To put MLM results into perspective, the highest EBI score (table 3 (61.3) contributed approximately 3 units to the CSI score compared to the lowest EBI score (15.8) which

contributed only .08 units to the CSI score (when the effects of survivor age, gender and time elapsed after stroke were accounted for). It is also important to note that the regression coefficient for time was only statistically significant at discharge ($p=.02$) suggesting that discharge point contributed most to carer strain levels, which is understandable. Overall, these results strongly suggest that the functioning level of RHS survivors is a very important contributor to carer strain and that the higher the survivor's dependency the greater the caring strain. Consequently, carers of highly dependent RHS survivors need more support to do their role. This is echoed by carer comments and regrets about how little some of the survivors could safely do for themselves and concerns about unpredictable behaviour.

Relationship between carers' strain and survivors' anosognosia

Findings from this study show a high percentage of anosognosia (about 70%) among stroke survivors observed prior to discharge. This tended to decrease once the survivors were living in the community but remained relatively high (27.8%) up to 6 months following stroke. This observation is consistent with cognitive recovery patterns and anosognosia incidence reported in the literature [45].

Anosognosia scores clearly predicted carer strain (even when statistically adjusted for HI status, differences in stroke severity and time after stroke). Despite its predictive importance, anosognosia is not routinely included in stroke research or studies on carer strain [45]. The current findings have implications for caring, education and therapeutic support received by carers of RHS survivors and rehabilitation professionals.

Anosognosia presents important ethical, behavioural and management implications in affected RHS conditions [40,45] especially when it coexists with emotional dysregulation. Understanding the survivor's ability to regulate emotions such as anger (reported by carers) could help develop therapeutic interventions and training aimed at supporting both carer and survivor overcoming some of the communication and behavioural challenges reported by

carers in the qualitative survey. It is not clear how relational and behaviour-specific carer's education and training is or if they receive any at all. However, appropriate support is important as carers of RHS survivors recognise the need for counselling and acknowledge their lack of skill to manage survivors who were "too demanding", "difficult to reason with", "angry and forgetful" and "in denial of his/her abilities" (2b, 2c), "fixing problems" when they occur. Carers felt that their skills were lacking in this area.

Whilst it is good practice for therapists to discuss anger with clients, it is more difficult to know what to do, what to advise and how best to manage a challenging situation on a regular basis. Arguably, survivors with reduced awareness of stroke consequences may resent efforts from carers to assist and keep them safe (e.g. as in fall prevention) which may in turn manifest itself as anger in the survivor. It is clear that there are ethical issues in need of consideration by professionals working with RHS carer-survivor dyads, associated with denial and lack of awareness of illness among some stroke survivors. Such issues are easier to identify from in-depth discussion with the carers and assessment of survivors for anosognosia. However, the lack of research and appropriate validated tools in this area is concerning and in need of urgent development [45].

Relationship between carer strain and number of voiced concerns

MLM results supported a predictive relationship between carer strain and the number of caring concerns reported by the carer, even when survivor age, time and carer depression are considered. In general, less stressed carers report fewer concerns and vice versa supported by similar findings studies [46,47] who reported on positive and negative aspects of caring experiences. In relation to the current study, the result makes sense considering that more than half of the survivors had severe strokes and were relatively low functioning. For example, the median EBI scores at discharge and six weeks after were 35 and 46, which means that half of the sample scores lie below these values, indicating significant dependency

on carer assistance. In turn, this increases the risk of carer strain, which is in agreement with the qualitative reports from carers that the time around discharge and immediately after is highly stressful. Further evidence comes from the type and pattern of concerns reported, this was highest at discharge (207) and 6 weeks post (218) compared to stroke onset (108) and 6 months post (174). This pattern suggests that carer concerns change over time hence time is of essence when planning carer support [30] if it is to alleviate carer burden and smooth transitions. It is also reasonable to assume that the type of carer concern matters. Referring to table 4/last column it is clear that certain categories have many more comments in them, some as high as 103 e.g. health and well-being (1a), information provision and training (1e) 86, behaviour and safety (2b) 78 comments. Most likely, the amount of comments reflects the relative importance of specific concerns to the carers in this sample.

The carers provided examples of concern and perceived stress such as difficulties reasoning with an angry, forgetful, demanding, impulsive and unrealistic survivor. This is rather surprising, given the high levels of cognitive function measured by the MEAMS. Plausible explanations include measurement error and tool limitations. However, looking at the overall picture, there are consistently high self-efficacy levels, which suggest unusually high levels of self-belief by the survivor in their own abilities to cope. In fact, this observation is quite common in clinical settings [19,45]. It is consistent with the high levels of anosognosia and unrealistic expectations among survivors reported by carers in the surveys. Arguably, those survivors with reduced awareness of illness probably also have impaired situational judgement which is likely to adversely affect their decision making abilities and hence their behaviour. In support of this view, self- efficacy (GSE) was not an important contributor to carer strain (when modelled with overall functional independence (EBI scores) but anosognosia scores were predictive. Overall, these results point to very complex dynamics between the interdependent factors associated with recovery from RHS and the reality of

caring for highly dependent RHS-survivor with subtle psychological impairments. This has important implications for the preparation of carers prior to discharge. There is a large body of behavioural psychology that could be used to develop and enhance content of carer support interventions in this area e.g. in equipping carers on a regular basis with appropriate skills to manage unrealistic expectations and challenging behaviour from the survivor.

In the current study, survivors' mobility (PASS score) was unrelated to carer strain. This finding is consistent with reports in the literature that, carers tend to be less stressed by physical rather than cognitive impairment [40]. It is also supported by MLM results, which suggest that the contribution of cognitive ability was relatively more important than that of overall functional ability (when modelled together). Another explanation could be that stroke survivors in general tend towards a sedentary life-style and are more protected by carers, their comments suggest that they fear the survivor is not safe mobilising and/or that it is too stressful for them to oversee. Consequently, they may avoid the need to mobilise as a way of coping, and to reduce risk of falling and possible conflict.

Conclusion

Findings from this study support the need for early recognition and implementation of psychosocial support and practical strategies (preparation, education and training) targeted towards the identified needs of carers of RHS survivors. Caring experience seems enhanced by a sense of working together and being understood by the “other” person (the survivor) and healthcare professionals. **Considering the main factors that contribute to carer strain in RHS survivors (low functioning levels and cognitive-behavioural problems) rehabilitation professionals could address carer-survivor issues as a functioning unit rather than as separate entities. Future research should focus on the impact of relationship dynamics on carer and RHS survivor outcomes.**

Implications

There is a need for thorough, regular assessment of RHS-survivor skills; specifically anosognosia and neuro-behavioural impairments. It is imperative that the carer feels comfortable to bring up issues with challenging behaviour so that rehabilitation professionals can help address these appropriately.

In the context of right hemisphere stroke:

- Carer assessment should be comprehensive and include a measure of perceived ability to care.
- Less strained carers tend to report fewer caring concerns and have lower depression levels.
- Education, training and practical support should be tailored to carer identified needs, abilities and the caring context.

The main limitation of the study is sample size. A larger dataset would have enabled testing for interactions between modelled factors.

Although the measures used in the design were valid and appropriate, it is possible for inherent limitations to influence the results (e.g. the MEAMS and self-efficacy scale, which are not stroke-specific). The possibility that other factors than those measured in this study may contribute to carer strain should also be considered when interpreting the results.

References

1. National Audit Office (2010) Department of Health: progress in improving stroke care. London: HMSO.
2. Bakas T, Kroenke K, Plue L, et al. Outcomes among family caregivers of aphasic versus non-aphasic stroke survivors. *Rehabil Nurs*. 2006;31(1):33-42.

3. Luker J, Murray C, Lynch E, et al. Carers' experiences, needs, and preferences during inpatient stroke rehabilitation: a systematic review of qualitative studies. *Archives of physical medicine and rehabilitation*. 2017;98(9), 1852-1862
4. Aziz, N, Pindus D, Mullis R et al. Understanding stroke survivors' and informal carers' experiences of and need for primary care and community health services—a systematic review of the qualitative literature: protocol. *BMJ*. 2016;6(1), e009244
5. Bulley C, Shiels J, Wilkie K, et al. Carer experiences of life after stroke—a qualitative analysis. *Disabil Rehabil*. 2010;32(17):1406-1413.
6. Byun E, Evans L. Concept analysis of burden in caregivers of stroke survivors during the early post stroke period. *Clin Nurs Res*. 2015;24(5):468-486.
7. Honea N, Colao D, Somers S. Putting Evidence Into Practice: nursing assessment and interventions to reduce family caregiver strain and burden. *Clin J Oncol Nurs*. 2008;12(3):507-516.
8. Ellis-Hill C, Robinson J, Wiles R, et al. Going home to get on with life: patients and carers experiences of being discharged from hospital following a stroke. *Disabil Rehabil*. 2009;31(2):61-72
9. Legg L, Drummond A, Leonardi-Bee J, et al. Occupational therapy for patients with problems in personal activities of daily living after stroke: systematic review of randomised trials. *Br Med J*. 2007;335(7626):922.
10. Intercollegiate Stroke Working Party. National clinical guideline for stroke. 5th edition. London: Royal College of Physicians Clinical Effectiveness and Evaluation Unit 2016.

11. Le Dorze G, Signori F. Needs, barriers and facilitators experienced by spouses of people with aphasia. *Disabil Rehabil.* 2010;32(13):1073-1087.
12. Howe, T, Davidson B, Worrall L, et al. 'You needed to rehab... families as well': family members' own goals for aphasia rehabilitation. *Int J Lang Commun Dis.* 2012;47(5):511-521.
13. Grawburg M, Howe T, Worrall L, et al. A qualitative investigation into third-party functioning and third-party disability in aphasia: Positive and negative experiences of family members of people with aphasia. *Aphasiology* 2013;27(7):828-848.
14. Greenwood N, Mackenzie A, Cloud G, et al. Informal carers of stroke survivors—factors influencing carers: a systematic review of quantitative studies. *Disabil Rehabil.* 2008;30(18):1329-1349.
15. Hultman M, Everson-Rose S, Tracy M, et al. Associations between characteristics of stroke survivors and caregiver depressive symptoms: a critical review. *Top Stroke Rehabil.* 2019;1-10.
16. Minshall C, Pascoe M, Thompson D, et al. Psychosocial interventions for stroke survivors, carers and survivor-carer dyads: a systematic review and meta-analysis. *Top Stroke Rehabil.* 2019;1-11
17. Cherney L. Ethical issues involving the right hemisphere stroke patient: To treat or not to treat? *Top Stroke Rehabil.* 2006;13(4):47-53.
18. Kortte K, Hillis A. Recent advances in the understanding of neglect and anosognosia following right hemisphere stroke. *Curr Neurol Neurosci Rep.* 2009;9(6):459-465.
19. Kottorp A, Ekstam L, Petersson L. Differences in awareness between persons with left and right hemispheric stroke. *Scand J Occup Ther.* 2013;20(1):37-44.

20. Blonder L, Langer S, Pettigrew L, et al. The effects of stroke disability on spousal caregivers. *Neuro Rehabil.* 2007;22(2):85-92.
21. Williams S. The impact of aphasia on marital satisfaction. *Arch Phys Med Rehabil.* 1993;74(4):361-367.
22. Buxbaum LJ, Ferraro M, Veramonti T, et al. Hemispatial neglect subtypes, neuroanatomy, and disability. *Neurology* 2004;62(5):749-756.
23. Brott T, Adams H, Olinger C, et al. Measurements of acute cerebral infarction: a clinical examination scale. *Stroke* 1989;20(7):864-870.
24. Prosiegel M, Böttger S, Schenk T, et al. Der erweiterte Barthel-Index (EBI)—eine neue Skala zur Erfassung von Fähigkeitsstörungen bei neurologischen Patienten. *Neurol Rehabil.* 1996;1:7-13.
25. Benaim C, Pérennou D, Villy J, et al. Validation of a standardized assessment of postural control in stroke patients: the postural assessment scale for stroke patients (PASS). *Stroke* 1999;30(9):1862-1868.
26. Golding E. MEAMS: the Middlesex Elderly Assessment of Mental State. Titchfield (Hampshire): Thames Valley Test Company 1989.
27. Cutting J. Study of Anosognosia. *J Neurol Neurosurg Psychiatry.* 1978;41(6):548-555.
28. Jerusalem M, Schwarzer R. Self-efficacy as a resource factor in stress appraisal processes. *Self-efficacy: Thought control of action.* 1992;195213.
29. Wilson B, Cockburn J, Halligan P. Behavioural inattention test. London: Thames Valley Test Company 1987.

30. Yesavage J, Sheikh J. Geriatric Depression Scale (GDS) recent evidence and development of a shorter version. *Clin Gerontol.* 1986;5(1-2):165-173.
31. Robinson B. Validation of a Caregiver Strain Index. *J Gerontol.* 1983;38(3): 344-348.
32. IBM Corp. Released 2011. IBM SPSS Statistics for Windows, Version 20.0. Armonk, NY: IBM Corp.
33. Rasbash J, Charlton C, Jones K, & Pillinger, R. (2017) Manual supplement for MLwiN Version 3.01.
34. Snijders T, Bosker J. *Multilevel Analysis: An Introduction to Basic and Advanced Multilevel Modeling*, second edition. London (UK): Sage Publishers; 2012
35. Blake H, Lincoln N. Factors associated with strain in co-resident spouses of patients following stroke. *Clin. Rehabil.* 2000;14(3):307-314.
36. Cheng J, Edwards L, Maldonado-Molina M, et al. Real longitudinal data analysis for real people: building a good enough mixed model. *Stat Med.* 2010;29(4):504-520.
37. Dong Y, Peng C. *Principled missing data methods for researchers.* Springer Plus 2013; (2(1):222.
38. Di Monaco M, Schintu S, Dotta M, et al. Severity of unilateral spatial neglect is an independent predictor of functional outcome after acute inpatient rehabilitation in individuals with right hemispheric stroke. *Arch Phys Med Rehabil.* 2011;92(8):1250-1256.
39. Nijboer T, Van de Port I, Schepers V, et al. Predicting functional outcome after stroke: the influence of neglect on basic activities in daily living. *Front Hum Neurosci.* 2013;7(182):9-14

40. Visser-Keizer A, Jong B, Deelman B, Berg I, et al. Subjective change in emotive, cognition and behaviour after stroke: factors affecting the perception of patients and partners. *J Clin Exp Neuropsychol*. 2002;24(8):032-1045.
41. Twisk JW. *Applied multilevel analysis: a practical guide for medical researchers*. Cambridge university press; 2006
42. Gale N, Heath G, Cameron E, et al. Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Med Res Methodol*. 2013;13(1):117.
43. Greenwood N, Pelone F, Hassenkamp A. General practice based psychosocial interventions for supporting carers of people with dementia or stroke: a systematic review. *BMC family practice*, 2016;17(1), 3.
44. Ostwald S, Bernal M, Cron S, et al. Stress experienced by stroke survivors and spousal caregivers during the first year after discharge from inpatient rehabilitation. *Top Stroke Rehabil*. 2009;16(2):93-104.
45. Jenkinson P, Preston C, Ellis S. Unawareness after stroke: A review and practical guide to understanding, assessing, and managing anosognosia for hemiplegia. *J Clin Exp Neuropsychol*. 2011;33(10):1079-1093.
46. Mackenzie A, Greenwood N. Positive experiences of caregiving in stroke: a systematic review. *Disabil Rehabil*. 2012;34 (17):1413–22.
47. Klinedinst N, Gebhardt M, Aycock D, et al. Caregiver characteristics predict stroke survivor quality of life at 4 months and 1 year. *Res Nurs Health* 2009;32(6):592-605.

Table 1 Description of carer and survivor measures employed in the study

Stroke survivor measures		
Assessment tool and (abbreviation)	Description	Scale
Extended Barthel Index (EBI) [24]	Consists of 16 items, assesses dependency levels in eating, drinking, dressing, bathing, wheelchair to bed transfer, locomotion, stairs, toilet, bladder and bowel control*, cognitive functioning including problem solving, orientation, memory and learning, communication & social interaction, on a 4-point scale & accounts for time taken to complete each activity.	0 to 64; 0 is the lowest functional ability level attainable.
The Postural Assessment scale for Stroke (PASS) [25]	Measures static & dynamic core balance & posture control skills in sitting, standing & during transfers from lying to sitting to standing & reaching. A score of 30 to 36 implies that the patient has standing balance and is ambulant for short distances (~5 meters on level surface).	0 to 36; the higher the score the better the balance
The Middlesex Elderly Assessment of Mental State (MEAMS) [26]	Consists of 12 items, assesses cognitive and perceptual dysfunction in orientation, memory, communication, numeracy, spatial construction skills, object discrimination and motor perseveration.	0 to 12; 0 to 7 indicate impairment, 8 to 9 borderline & 10 to 12 within normal range.
Anosognosia Questionnaire (AQ)** [27]	The researcher rated the client's verbal response as true or false for a set of five questions regarding the perception of stroke and its consequences. Anosognosia was recorded as, present when elicited by at least one question.	0 to 1; anosognosia present (1), absent (0)
The General Self-efficacy Scale (GSE) [28]	Consists of 10 items, assesses a person's self-belief in their abilities to cope with adverse situations. Each item is rated on a 4-point scale.	10 to 40; the higher the overall score, the higher the levels of self-efficacy.
The Behavioural Inattention Test (BIT) [29]	Conventional section used to measure HI severity. The BIT battery consists of 6 pen and paper subtests in which the client is required to cross out targets, bisect lines, copy figures and shapes and draw familiar objects from memory. It is not timed and the percentage error of missed targets in the overall score provides a measure of HI severity (Stone et al 1987).	0 to 146; 129 is cut-off point between impaired (0 to 128) and healthy HI levels (129 to 146).
Carer measures		
The Geriatric	Consists of 15 items, which assess somatic &	0 to 15;

Carer Strain and Right hemisphere dysfunction

Depression Scale (GDS-15) [30]	affective depressive symptoms, carer rates each item on a dichotomous scale.	0-4 considered normal, 5-8 mild, 9-11 moderate & 12-15 severe depression (Greenberg et al 2007)
The Caregiver Strain Index (CSI) [31]	Consists of 13 items designed to identify strain in informal care providers, it is self-rated, each item is scored on a dichotomous scale.	0 to 13; Scores equal to or greater than 7 considered as abnormally high.

*Continence levels were determined from medical records and community follow-up assessments.

**modified in line with Buxbaum and colleagues [22]

Table 2 Demographic details for 51 carer-survivor dyads

		Stroke survivor	Carer
Age/years (mean \pm SD [range])		75.8 \pm 9.8 [46-92]	7 (13.7%) [30-50 years] 44 (86.3%) [50-80 years]
Gender (male)		23 (45%)	13 (25.5%)
Stroke severity (NIHSS Scale)	Mild	1 (1.9%)	Not applicable
	Moderate	21 (41.1%)	
	Severe	29 (57.0%)	
In-patient rehabilitation (days)		30.8 \pm 22.0 [5-86]	Not applicable

Table3 Descriptive statistics for all participants at baseline and follow-up assessment time-points, median (upper, lower quartile) scores and percentage proportions

Measured factor	T0	T1	T2	T3
Survivor	(n=51)	(n=51)	(n=45)	(n=43)
Functional ability	24.5 (15.8, 36.3)	35.0 (24.0, 49.0)	46.5 (30.0, 57.5)	51.5 (37.5, 61.3)
Self-efficacy	33.0 (29.0, 36.0)	31.5 (26.8, 36.0)	31.5 (26.8, 37.0)	32.0 (25.0, 37.0)
Balance	16.0 (5.5, 25.5)	22.0 (11.3, 29.0)	28.0 (15.3, 33.0)	27.5 (24.3, 33.0)
Cognitive	9.0 (4.0, 11.0)	9.0 (7.0, 11.5)	11.0 (9.0, 12.0)	11.0 (9.0, 12.0)
% rate with Anosognosia	72.7%	71.4%	42.5%	27.8%
% rate with abnormal HI levels	56.5%	52.3%	38.5%	35.3%
% rate bladder dysfunction	46.7%	40.0%	34.0%	29.0%
% rate bowel dysfunction	46.7%	35.6%	31.7%	24.3%
Carer	(n=51)	(n=51)	(n=45)	(n=43)
Carer strain	4.0 (3.0, 6.3)	5.0 (3.0, 7.0)	4.0 (2.0, 6.3)	3.5 (2.0, 6.3)
Depression	2.0 (1.0, 4.0)	3.0 (1.0, 5.0)	3.0 (1.0, 5.0)	3.0 (1.0, 6.3)
Number of concerns	183	207	218	174
Abbreviations: Baseline (T0), discharge (T1), 6 weeks post-discharge (T2), 6 months since stroke (T3), Hemi-inattention (HI), n=number				

Table 4 Breakdown of carer concerns grouped by theme, category and time post stroke

Theme 1 - Carer concerned about self in relation to:		T0	T1	T2	T3	Total
Categories						
a	Own health & wellbeing	15	23	25	40	103
b	Own safety	4	8	5	1	18
c	Relationship with survivor/QOL	6	11	8	10	35
d	Suitability of accommodation and equipment provision	23	13	14	3	53
e	Information provision and training	29	31	11	15	86
f	Medication - sorting and administration	4	2	0	0	6
g	Adequacy and appropriate support service provision	0	24	14	0	38
h	Communication with rehabilitation teams	0	0	15	11	36
i	Finances	0	0	0	10	10
j	Availability – ‘no time to think and do things’	0	27	17	15	59
k	Social and participatory restrictions	0	0	17	13	30
Theme 2 - Carer concerned about survivor in relation to:						
a	Health & wellbeing	15	33	31	16	95
b	Behaviour and safety	27	16	20	15	78
c	Abilities and extent of recovery	38	0	32	25	95
d	Therapy – amount	22	8	9	0	39
Total concerns		183	207	218	174	782
Abbreviations: Baseline (T0), discharge (T1), 6 weeks post-discharge (T2), 6 months since stroke (T3), Quality of life (QOL)						