

## Research paper

# British Indian carers of stroke survivors experience higher levels of anxiety and depression than White British carers: findings of a prospective observational study

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### What we know

- Up to 40% of carers report significant carer strain. Consequences of increased carer strain include unsuccessful rehabilitation, poorer physical and psychosocial outcomes for stroke survivors, and high rates of institutionalisation.
- Though caregiver strain depends in part on the severity of the initial stroke, the level of disability caused, and the level of care needed by the stroke survivor, carer characteristics are also important.
- The supplementation of information and emotional support with specific training in basic nursing skills and activities of daily living facilitation is beneficial, in terms of carer outcomes, at least in a white, middle class population.
- For minority ethnic groups, we do not know whether the same factors predict carer strain as for the majority, or whether the same interventions, aimed at alleviating it, are beneficial.

### What this paper adds

- British Indian carers reported higher levels of depressive symptoms than White British carers.
- British Indian stroke survivors were more likely to have significant cognitive impairment.
- We found no significant differences in either the incidence or predictors of carer strain between White British and British Indian carers, using our prespecified definitions of carer strain.
- Levels of reported depression, and anxiety and depression combined, were significantly higher in the British Indian carers, and levels of physical activity among carers were lower.

## ABSTRACT

Carers of stroke survivors face significant burdens, and increased carer strain has negative implications for both the stroke survivor and the carer. There are limited data on carer strain in the British Indian UK population. In a prospective cohort of White British and British Indian stroke survivors and their carers, we report the incidence of carer strain in each ethnic group, describe patient and carer characteristics, and identify predictors of increased carer strain. Forty-nine participants and their carers were of White British origin and 24 of Indian ethnic origin, whose first language was Gujarati or Punjabi. Multidimensional outcome measures were used to assess the physical and cognitive function in stroke survivors at one month and 3–6 months (final follow-up) from stroke onset. Levels of carer strain were assessed at the same time points using the Carer Strain Index and the Hospital Anxiety and Depression Scale. Statistical significance for difference in patient and carer characteristics between White British and British Indian groups was assessed. Logistic regression models were used to identify

predictors of carer strain. British Indian stroke survivors had poorer scores on cognitive assessment (Mini Mental State Examination median 21, IQR 10.5–26.5 in British Indian, versus median 28.5, IQR 20–30,  $p=0.001$ ) at one month. British Indian carers were younger, and reported higher levels of anxiety and depression at one month (median Hospital Anxiety and Depression Scale subscore depression 3.5 in White British, versus 7 in British Indian,  $P=0.002$ , median hospital anxiety and depression score total 10, versus 14,  $P=0.012$ ). Twenty-four percent of all carers showed evidence of elevated carer strain (CSI>6) at one month, and 30% at final follow-up. There were no differences in levels of carer strain between the two ethnic groups. These findings will inform future research, and in turn, may help to guide population-targeted interventions aimed at reducing carer strain.

**Keywords:** British Indian, carer strain, depression, ethnic minority, informal carers, South Asian, stroke, White British

## Introduction

Stroke is the second leading cause of death and leading cause of long-term disability worldwide (Lozano, 2012); it is currently the single largest cause of severe adult disability in England (Mant *et al*, 2004), with dramatic impacts on survivors, but also on carers (Legg and Drummond, 2007). More than 900,000 people are currently living with the effects of stroke (National Audit Office, 2006), and up to 80% of survivors rely on informal carers (Anderson *et al*, 1995). Although there may be positive aspects to caring, (Kinney *et al*, 1995; Chappell and Dujela 2008; Greenwood *et al*, 2009), there are also significant burdens (Chappell and Dujela, 2008; Greenwood *et al*, 2009). In addition to the primary impact of stroke, survivors may suffer from a number of physical and psychosocial complications, including immobility, falls, incontinence, cognitive impairment, and depression (Davenport *et al*, 1996). Stresses and burdens experienced by caregivers of stroke patients may therefore be substantial. Furthermore, caregivers may have multiple demands from other aspects of their lives or their own health problems (Anderson *et al*, 1995).

Caregiver burden can be defined as “alterations in caregivers’ emotional and physical health, which occur when care demands outweigh available resources”. Carer strain is defined when caregivers “feel difficulty

in performing the caregiver role”, as the result of an accumulation of stresses perceived by informal carers (Archbold *et al*, 1990; Given *et al*, 1992). Role changes, increased responsibilities, financial burdens, lack of information or specialist training in providing care, and changes in family roles are a few of many potential sources of stress or burden that may contribute toward increased carer strain. Caring is associated with a high risk of disrupting caregivers’ work and leisure, family life and quality of life. High burden and perceived carer strain can result in deterioration of carers’ own health status, social life and well-being (Low *et al*, 1999). Up to 40% of carers of stroke survivors demonstrate significant carer strain six months following the stroke (Blake and Lincoln, 2000), and nearly all caregivers experience adverse effects on their emotional health one year after a stroke (Anderson *et al*, 1995). Informal caregivers who report high levels of carer strain are at risk for premature mortality, stroke and cardiovascular disease (Schulz and Beach, 1999).

For stroke survivors, increased carer strain risks unsuccessful rehabilitation (Carnwath *et al*, 1987), poorer physical and psychosocial outcomes (King 1996), high rates of institutionalisation (Bamford *et al*, 1986), and reduction in quality of care. The burden of caring can be predicted from increasing patient dependency and stroke severity (Carnwath *et al*, 1987, Dennis *et al*, 1998). Carer characteristics are also relevant including physical health symptoms and psychosocial factors (Carnwath *et al*, 1987), particularly with respect

to concerns regarding future care (Reimer *et al*, 1998), social isolation (Carnwath *et al*, 1987), unmet requests for support and information (Anderson *et al*, 1995), financial implications of lost earnings and buying in support, and occupational loss (Kniepmann, 2012).

Early recognition of caregivers at risk of increased strain may allow targeting of interventions to help prevent or resolve ongoing problems, and thus improve patient and carer outcomes. However, studies assessing the effects of stroke survivor and carer education, counselling, emotional support and specific assistance in accessing services have reported little impact on patient and carer outcomes (Forster and Young 1996; Mant *et al*, 2000). Information and emotional support with specific training in basic nursing skills and activities of daily living is beneficial, at least for a (White), middle class, urban population (Kalra *et al*, 2004).

The UK 2011 Census reports just over 5% of England and Wales population being of South Asian origin. Leicester has a high proportion of people of Indian origin, mainly Gujarati and Punjabi speakers, who represent over 28.3% of the total population (Leicester City Council, 2011). South Asian elders are at high risk of stroke (Chaturvedi, 2003). The Leicestershire Community Stroke and Ethnicity Study (LCSES) reported that more South Asian patients were likely to be discharged home and to have informal carers at home. They were more likely to be younger and moderately or severely disabled, which may predispose to increased carer strain (Hsu *et al*, 1999). Perry *et al* (1999) found a lower uptake of professional health and social support among South Asians because of the inadequacy of translated material, inappropriate religious and cultural stances, and lack of awareness of available services. It is clearly important to establish the causes and predictors of carer strain to develop and target interventions to reduce strain, particularly in an ethnic minority population where interventions may be further affected by cultural acceptability and language. We describe carer strain in carers of White and British Indian stroke survivors, and describe differences in patient and carer characteristics between the two groups in a prospective observational study.

## Aims

The overall aim of this study was to support the future development of a population-targeted intervention to reduce carer strain. We used quantitative and qualitative methodology in a prospective, cohort study of hospital-admitted White British and British Indian stroke survivors and their carers to

- investigate the clinical and psychosocial differences between White and British Indian stroke patients and their carers
- identify the differences in levels of carer strain between the two groups; to identify the predictors of increased carer strain in White British and British Indian populations
- to identify any differences in predictors between the two ethnic groups.

The quantitative findings from our study are presented here; with the qualitative study results to be described elsewhere. This study was approved by the Nottingham Research Ethics Committee, East Midlands (09/H0403/95).

## Methods

### Study population

Stroke survivors recruited were of White British and Indian ethnic origin, whose first language was English, Gujarati or Punjabi. Participants were anticipated to survive for at least one month following their admission for first-ever or recurrent stroke to the University Hospitals of Leicester NHS Trust, to enable outcome data collection at the first outcome point, and have an identified informal carer. Stroke survivors with no/mild physical disability were also included to allow study of other impairments following stroke, e.g. aphasia, cognitive impairment, on indices of carer strain. Data collection and outcome measures were collected by staff fluent in Gujarati and Punjabi, to ensure assessments and interviews were undertaken in each participant's first language. Stroke survivors and carers provided formal consent to participate in the project.

### Measures

Multidimensional outcome measures were used to assess physical and cognitive function in stroke survivors, as well as levels of anxiety and depression. The following baseline data were collected in all stroke survivors: socio-demographic characteristics; clinical characteristics including stroke severity by National Institute of Health Stroke Scale (NIHSS) and stroke type by Oxford Community Stroke Project Classification; pre morbid function (Barthel Index, Frenchay Activity Index), and handicap (Modified Rankin Score); place of care. For stroke survivors at one month or hospital discharge and at final follow-up (3 to 6 months), Barthel Index; Frenchay Activity Index; Modified Rankin Scale Score; Mini Mental State Examination (MMSE); Hospital and Anxiety and Depression Score; Short Form 36 (Table 1) were recorded.

**Table 1** Explanation of assessment scales

Scale	Description	Scoring system
NIHSS: National Institutes of Health Stroke Scale (NIH Stroke Scale International: The International Electronic Health Education Network 2010)	Measures the severity of symptoms associated with stroke, providing a quantitative measure of neurological deficit post stroke	Scores range 0–42. Higher scores indicate greater severity. Stroke severity may be stratified on the basis of NIHSS scores: Very Severe: >25 Severe: 15–24 Mild to Moderately Severe: 5–14 Mild: 1–5
Oxford Community Stroke Project Classification	Divides people with stroke into four different categories, according to the symptoms and signs with which they present. This classification is useful for understanding the likely underlying pathology	TACS = Total anterior circulation stroke (most severe) PACS = Partial anterior circulation stroke LACS = Lacunar stroke (least severe) POCS = posterior circulation stroke
Mini Mental State Examination (MMSE)*	A brief screening tool to provide a quantitative assessment of cognitive impairment and to record cognitive changes over time. Consists of 11 simple questions or tasks grouped into 7 cognitive domains	Scores range from 0–30 with scores < 24 generally accepted as indicating the presence of cognitive impairment
Barthel Index (BI) (Rehab Measures Database 2013)	Assesses the ability of an individual with a neuromuscular or musculoskeletal disorder to care for him/herself. Assesses ability to perform 10 ADL/mobility activities	Items are rated based on the amount of assistance required to complete each activity. Scores range from 0–20 with higher scores indicating greater independence
Modified Rankin Scale (mRS) (Rehabilitation Measures Database 2013)	Categorises level of functional independence with reference to pre-stroke activities	Scored from 0–5 (higher score indicates greater disability): 0. No symptoms 1. No significant disability despite symptoms; able to carry out all usual duties and activities 2. Slight disability: unable to carry out all previous activities but able to look after own affairs without assistance 3. Moderate disability: requiring some help, but able to walk without assistance 4. Moderately severe disability: unable to walk without assistance, and unable to attend to own bodily needs without assistance 5. Severe disability: bedridden, incontinent, and requiring constant nursing care and attention

\* The MMSE is subject to copyright. Individual MMSE test forms were purchased from Psychological Assessment Resources (PAR).

**Table 1** Continued

The Short Form 36 (SF36) (Rand Health 2010)	A generic, patient-report measure designed to assess health-related quality of life (SF36), in eight separate domains: Physical functioning, role limitations due to physical health, role limitations due to emotional problems, energy/fatigue, emotional wellbeing, social functioning, pain and general health	Reported as scores 0–100 (higher score for more favourable health state) in each of the eight domains
Hospital Anxiety and Depression Score (HAD) (Rehab Measures Database 2013)	A two-dimensional scale developed to identify depression and anxiety among physically ill patients. Consists of 14 items, divided into two 7-item subscales: Anxiety (HADS-A); items reflect a state of generalized anxiety Depression (HADS-D); focus on the concept of anhedonia	Total score is out of 42 (21 per subscale). Higher scores indicate greater levels of anxiety or depression. The total HADS score may be regarded as a global measure of psychological distress
Frenchay Activity Index (FAI) (Rehabilitation Measures Database 2013)	Assesses a broad range of higher levels of physical function or “non ADL” activities in patients recovering from stroke, e.g. shopping, reading, cooking. Can be separated into three factors: Domestic chores, Leisure/work, Outdoor activities	Provides a summed score 15–60, with higher scores indicating greater frequency of performing the various activities (15=no activities, 60=full activities)
Caregiver Strain Index (CSI) (Robinson 1983)	The most commonly used tool for estimating caregiver burden. Contains 13 dichotomous yes/no questions related to strain.	Scores range from 0 (no strain) to 13 (maximum strain), with scores of $\geq 7$ regarded as indicating elevated carer strain or burden

Carer assessments were conducted at one month, and final follow-up (3 to 6 months). The Hospital Anxiety and Depression score (Table 1) includes two subscales, one for anxiety and one for depression. The original validation study suggested that a score of  $> 7$  on either subscale could be used to define a case of emotional illness on either subscale (Zigmund and Snaith, 1983); a score of  $> 7$  indicating elevated carer strain. The Caregiver Strain Index (CSI) is a brief and easily administered screening instrument, containing 13 dichotomous yes/no questions related to strain. It is the most commonly used tool for estimating caregiver burden, with good reproducibility and moderate responsiveness in assessing caregiver strain in carers of stroke survivors (Marcel *et al*, 2007); a score of  $> 6$  is considered to represent high carer burden (Robinson, 1983). Where possible, assessment measures were chosen that had been translated, back translated and validated in Gujarati and Punjabi (Rait *et al*, 2000;

Mitchell *et al*, 2010). In addition to the quantitative assessments, stroke survivors and carers were interviewed in-depth at one month and at follow-up. Carers were asked to keep a daily diary of hourly activities over a period of six months. Results of the qualitative analysis will be reported separately.

### Statistical analysis

Statistical analysis was performed using IBM SPSS version 20. All data were analysed at a descriptive level and compared between British Indian and White British populations. Continuous variables are presented as mean plus standard deviation (SD) if normally distributed, and median (interquartile range) if not. Categorical variables are presented as percentages. Statistical significance for difference between groups was assessed by Student's *t* test or Mann Whitney U

test for continuous variables and by Pearson's chi squared or Fisher exact test for categorical variables. Significance was set at the 5% level.

Two main dichotomised outcome measures were used to indicate the presence of carer strain at one month, and final follow-up (3 to 6 months): Caregiver Strain Index  $>6$ , and Hospital Anxiety and Depression score  $>7$  on either subscale. The group was analysed as a whole, and with White British and British Indian populations as separate groups. Predictor variables entered into the regression models for one month carer strain were: stroke survivor age; carer age; stroke severity at onset (NIHSS); and Barthel Index, MMSE, Frenchay Activity Index and Modified Rankin Scale Score at one month. The significance ( $P<0.05$ ) of each variable was assessed in the presence of the other six variables. For final (3 to 6 month) carer strain, the following predictor variables were used: stroke survivor age; carer age; stroke severity at onset (NIHSS); and Barthel Index, MMSE, Frenchay Activity Index and Modified Rankin Scale Score at follow-up.

Variables were entered into a logistic regression model, with either Hospital Anxiety and Depression subscore (dichotomised at  $>7$ ) or CSI (dichotomised at  $>6$ ) as the dependent variable. Changes in the independent variables predictive of carer strain following stroke were compared at one month and final follow-up post stroke. We used the Model chi-square, and the Hosmer-Lemeshow fit tests to assess the fit of the regression models.

## Results

### Study population

Seventy-three stroke survivors and their carers were recruited, of which 49 stroke survivors were white (White British) and 24 British Indian. All carers were of the same ethnic origin as the stroke survivor for whom they provided care. Six of the British Indian stroke survivors were Punjabi speakers and 18 Gujarati. Sixty-three (86%) participants were assessed at one month and 49 (67%) at final follow-up. Seven stroke survivors died, 4 were lost to follow-up and 14 withdrew prior to completion of final assessments. Demographics of stroke survivors and carers were similar in both populations (Table 2), with the exception that British Indian stroke survivors had fewer higher qualifications and their carers were younger.

### Stroke survivor characteristics

This study included people who were independent prior to their stroke (median Barthel Index 20, median modified Rankin Scale score 0 in both groups). The

White British stroke survivor cohort engaged in more activities, such as domestic chores, leisure/work and outdoor sport, before their stroke, as measured by the Frenchay Activity Index (FAI, White British median 41, IQR 36–51, versus 34, IQR 16–20,  $P=0.011$ ). It is important to note that the FAI is designed to measure lifestyle, rather than ability to self-care (Holbrook and Skilbeck, 1983), and some of these activities may be culturally defined.

Most participants' strokes (63%) were cortical ischaemic events, based on the Oxford Community Stroke Project Classification; 4.5% had an intracranial haemorrhage. There were no significant differences between the two groups. At one month follow-up, significant differences were seen in stroke survivor MMSE scores, which were significantly lower in the British Indian group (median 21, IQR 10.5–26.5, versus 28.5, IQR 20–30,  $P=0.001$ ), with a higher proportion of the British Indian patients having moderate (MMSE 18–20) or severe (MMSE  $\leq 18$ ) cognitive impairment according to pre-specified MMSE categories, 42.8% versus 16.7%, ( $P=0.007$ ). FAI scores were lower in the British Indian stroke survivors (median 38, IQR 24 to 41, versus 44, IQR 34–49,  $P=0.008$ ). Barthel Index and Modified Rankin Scale scores were similar. In the general health domain of the short form SF36, better health scores were reported in the White British stroke survivor cohort (median 55.0, IQR 40–75 versus 37.5, IQR 30–58,  $U=206.5$ ,  $z=1.96$ ,  $P=0.05$ ). There were no significant differences in scores in other SF36 domains between White British and British Indian stroke survivors.

At final follow-up, stroke survivor MMSE scores were largely unchanged from the one-month assessment, and the British Indian cohort continued to have significantly lower MMSE scores. Sixty-two percent of British Indian stroke patients had moderate to severe cognitive impairment on the MMSE, compared to 6% of White British stroke survivors ( $P=0.001$ ). No significant differences were observed in Modified Rankin Scale, Barthel Index, FAI or SF36 domain scores at long-term follow-up.

### Carer characteristics and carer strain indices

Statistically significant differences were seen in carer age, which was lower in British Indian carers (mean 58.3 versus 66.1 years,  $P=0.014$ ), and in the distribution of carers across age categories (Table 2). At one month, significant differences were seen in a number of carer assessments. FAI scores were higher in the White British carers, whilst total Hospital Anxiety and Depression scores and subscores for depression were significantly higher in British Indian carers (Table 4). The only significant difference between ethnic groups

**Table 2** Demographic data

	All	White British	British Indian	P value
Stroke survivor age (years)	70.6 (11.8)	70.0 (12.6)	71.0 (10.3)	
Stroke survivor age categories				
≤60 years	9 (12%)	6 (12.2%)	3 (12.5%)	NS
61–74	34 (46.6%)	23 (46.9%)	11 (45.8%)	
≥75	30 (41.1%)	20 (40.8%)	10 (41.7%)	
Stroke survivor gender				
Male	47 (64.4%)	34 (69%)	13 (54%)	
Female	26 (35.6%)	15 (31%)	11 (46%)	
Carer age (years)	63.4 (12.8)	66.09 (12.37)	58.25 (12.06)	
Carer age categories				
≤60	39.70%	30.60%	58.30%	
61–74	34.20%	36.70%	29.20%	
≥75	26.00%	32.70%	12.50%	
Accommodation				
Own home	73 (100%)	49 (100%)	74 (100%)	
Care home	0 (0%)	0 (0%)	0 (0%)	
Sheltered	0 (0%)	0 (0%)	0 (0%)	
Lives alone	4 (6.8%)	3 (6%)	1 (4%)	
Lives with carer	69 (93.2%)	46 (94%)	23 (96%)	
Stroke survivor qualifications				
Nil formal	40 (54%)	23 (47%)	17 (71%)	
GCSE/O level	15 (20%)	11 (22%)	4 (17%)	
A level	8 (11%)	7 (14%)	1 (4%)	
First degree	8 (11%)	7 (14%)	1 (4%)	
Higher degree	2 (3%)	1 (2%)	1 (4%)	

in the SF36 questionnaire scores was in role limitations due to emotional problems; British Indian carers reported worse scores (median 33.33, IQR 0–83 versus 66.32, IQR 33–100,  $P=0.035$ ). Median scores in the social functioning domain were notably higher in the White British carers (median 75, IQR 70–100, versus 50, IQR 6–93,  $P=0.056$ ). There was no statistically significant difference in the proportion of those with  $CSI>6$  at one month between the ethnic groups. Though the percentage of British Indian carers with a Hospital Anxiety and Depression subscore  $>7$  was notably higher than in the White British group (61.9% versus 40%,  $p=0.11$ ), this difference did not meet statistical significance (Table 4).

At final follow-up, there were no statistically significant differences in carer assessments or carer strain indices (Hospital Anxiety and Depression score, and CSI) between ethnic groups. A total of 41.2% of White British carers had a Hospital Anxiety and Depression subscale score  $>7$  versus 50% of British Indian carers ( $P=0.57$ ), and 30.3% of White British carers had a CSI score  $>6$ , versus 28.6% of British Indian carers

( $P=0.313$ ). Similarly, there were no statistically significant differences in scores on the SF36 questionnaire. This may be a consequence of a small sample size at final follow-up (34 White British carers, 13 British Indian carers).

### Predictors of carer strain at one month and follow-up

In the whole cohort (White British and British Indian), in an unadjusted model using continuous variables (odds ratios for caregiver strain index  $>6$  quoted for each unit increase in variable measure), statistically significant predictors of CSI  $>6$  at one month were stroke survivor age (OR 0.91, CI 0.858–0.985,  $P=0.017$ ), one month stroke survivor modified Rankin scale score (OR 3.507, CI 1.177–10.445,  $P=0.024$ ) and one month stroke survivor MMSE (OR 0.915, CI 0.837–0.999,  $P=0.044$ ). These results indicate that a higher score on the Modified Rankin Scale is associated with an increased likelihood of carer strain. Older stroke survivor age and higher scores on

**Table 3** Stroke severity and premorbid stroke survivor function

		All	White British	British Indian	P value
Oxford Stroke Classification:	TACS	16 (37%)	11 (22%)	5 (21%)	NS
	PACS	30 (41%)	18 (27%)	12 (50%)	
	LACS	11 (15%)	9 (18%)	2 (8%)	
	POCS	12 (16%)	9 (18%)	3 (13%)	
	ICH	4 (5%)	2 (4%)	2 (8%)	
NIHSS		6 (4–12.5)	6 (4–11)	6.5 (4–14.5)	NS
Pre morbid Barthel Index score		20 (18–20)	20 (19–20)	20 (16.25–20)	NS
Pre morbid Barthel Index categories	19–20	54 (74.0%)	38 (77.6%)	16 (66.7%)	NS
	15–18	10 (13.7%)	5 (10.2%)	5 (20.8%)	
	12–14	3 (4.1%)	3 (3%)	3 (12.5%)	
	<12	6 (8.2%)	3 (3%)	0 (0%)	
Pre morbid Frenchay Activity Index		41 (30.7–48)	44 (36–51)	32 (16.25–20)	0.01
Pre morbid Modified Rankin score		0 (0–1)	0 (0–1)	0 (0–1.75)	NS
Pre morbid Modified Rankin scale categories	0–2	6 (90.4%)	45 (91.8%)	21 (87.5%)	NS
	3–5	7 (9.6%)	4 (8.2%)	3 (12.5%)	

**Table 4** Carer assessments and CSI at one month

	All	White British	British Indian	P value
Frenchay Activity Index score	47.16 (42–52)	49 (46–55)	41 (37–47)	0.001
Hospital Anxiety and Depression Score total	11 (7–18)	10 (6–16)	14 (10–22)	0.01
Hospital Anxiety and Depression Score (anxiety)	7 (5–11)	7 (3.75–9)	9 (5.5–14)	NS
Hospital Anxiety and Depression Score (depression)	4 (2–7)	3.5 (1.75–5)	7 (4–9)	P=0.002
Hospital Anxiety and Depression Score: % with sub score over 7	51.20%	40.50%	61.90%	NS
Caregiver Strain Index	3 (1–6)	3 (1–6.5)	4 (2–6.5)	NS
Caregiver Strain Index score over 6	24.30%	24.40%	25%	NS

the MMSE are associated with a lower likelihood of carer strain (Table 5). The model chi-square was 1.97, (degrees of freedom 8,  $P=0.006$ ), indicating that adding the predictors to the model has a significant effect. The Hosmer and Lemeshow goodness-of-fit test gave a chi-square of 1.97 (degrees of freedom 8,  $P=0.982$ ), implying that the model estimated fit of the data to an acceptable level. At final follow-up, carer age was the only significant predictor of CSI  $> 6$  (OR

0.885, CI 0.68–0.95,  $P=0.048$ ), with older carer age reducing the likelihood of carer strain at final follow-up. Model chi-square and Hosmer and Lemeshow tests indicated acceptable fitting of the model.

In the unadjusted model using continuous predictor variables (odds ratios for Hospital Anxiety and Depression  $> 7$  on either subscale, for each unit increase in variable measure), stroke survivor FAI score (OR 0.917, CI 0.854–0.932,  $P=0.01$ ) was the only

**Table 5** Odds ratios for presence of carer strain (CSI>6) in the whole group at one month (OR quoted for every unit increase in predictor variable)

	Standard error	P value for OR	Odds ratio (OR)	95% CI for OR	
				Lower	Upper
Stroke survivor age	0.043	0.017	0.912	0.858	0.985
Carer age	0.042	0.706	1.016	0.856	1.13
Initial stroke severity (NIHSS)	0.080	0.618	0.961	0.822	1.124
One month Frenchay Activity Index	0.036	0.32	0.965	0.899	1.036
One month Barthel Index	0.116	0.088	1.219	0.971	1.530
One month modified Rankin Scale	0.557	0.024	3.507	1.177	10.445
One month MMSE	0.045	0.044	0.915	0.837	0.999

OR: Odds ratio.

NIHSS: National Institute for Stroke Score.

MMSE, Mini Mental State Examination.

Hosmer and Lemeshow test, chi squared 0.93,  $P=0.92$  (indicating a well-fitting model).

Model chi-square 1.97 with 8 degrees of freedom and  $P=0.006$ , indicating that adding the predictors to the model has a significant effect.

significantly associated variable with outcome at one month. This result implies that a higher FAI score is associated with a lower odds of a HADs subscore  $>6$ . A model chi-square of 16.65 ( $P=0.020$ ), and a Hosmer and Lemeshow goodness-of-fit test chi-square of 5.16 ( $P=0.739$ ) indicates an acceptable fit of the model. There were no significant associations with HADs  $>7$  on either subscale at final follow-up.

When analysed as two separate ethnic groups, we found no statistically significant predictors of carer strain at one month or final follow-up, and therefore could not go on to compare differences in predictors between ethnic groups. This is likely to be a consequence of small sample size.

## Discussion

Whilst we did not identify significant differences in the predictors of carer strain between the White British and British Indian groups, we do report relevant differences in stroke survivor and carer characteristics. These findings may help to guide population-targeted interventions aimed at reducing carer strain.

Twenty-four percent of carers showed evidence of elevated carer strain at one month, and 30% did at

final follow-up. When defined as Hospital Anxiety and Depression subscale score  $>7$ , 51.5% had elevated carer strain at one month, and 41% at final follow-up. Current literature is inconsistent regarding the incidence of carer burden or strain following stroke. Some studies have reported similar levels (Blake and Lincoln, 2000), whilst others have reported significantly higher levels, of up to 55% (Anderson *et al*, 1995; Dennis *et al*, 1998; Jen-Wen Hung *et al*, 2012). A more recent study reported much lower levels of carer strain (16%) at 8–12 months (Haley *et al*, 2009). Given significant heterogeneity in trial design and methodology (e.g. measure of carer strain, timing of assessments) and generally limited sample size, it is difficult to draw robust conclusions. This study adds to the existing evidence, and is the first report of carer strain incidence in British Indian carers of stroke survivors. However, the results should be interpreted with caution given the small numbers in the study.

Whilst CSI scores at both outcome intervals were similar, levels of reported anxiety and depression combined, and depression alone (on total Hospital Anxiety and Depression scale score, and on depression subscale score), were significantly higher in the British Indian carers at one month, and remained higher at final follow-up (non-significant). A non-significant trend toward higher anxiety subscale scores at both

follow up points was also seen in the British Indian carers. These findings may have important implications for stroke survivors and carers, given that previous studies in similar populations have found low carer mood and depression to be associated with increased carer burden and strain at longer-term follow-up (Blake and Lincoln 2000, Jen-Wen Hung *et al*, 2012). Large studies comparing Hospital Anxiety and Depression scores in the White British and British Indian populations are lacking. A recent study performed to assess the health status of South Asian and African-Caribbean UK residents using the EQ 5D score, a generic quality of life measure, reported that compared with the UK general population, substantially fewer African-Caribbean and South Asian participants reported problems with anxiety and depression when stratified by age (Calvert *et al*, 2012). A large study of White British and South Asian patients attending a diabetes screening clinic in Leicestershire reported no difference in levels of depression between the two groups, utilising the World Health Organisation-Five (WHO-5) Wellbeing Index, as a screening tool (Aujla, 2009). However, a cross-sectional survey of White British and British South Asian cancer patients in Leicestershire found nearly double the level of depression in the South Asian group with significantly higher self-reported rates of fatalism, helplessness, hopelessness and denial (Lord *et al*, 2013). Therefore, differences in levels of anxiety and depression reported in our study may be stroke related and cannot be attributed solely to differences in baseline characteristics between the ethnic groups.

Differences in certain stroke survivor and carer characteristics between the ethnic groups may also help explain the higher levels of depressive symptoms observed in the British Indian carers. Potentially relevant stroke survivor differences are lower levels of activity in the British Indian group (FAI score) and poorer cognition (MMSE scores). Both these variables were associated with carer strain at one month and have been reported as predictors of carer strain in previous studies (Dennis *et al*, 1998; Blake and Lincoln, 2000). Perhaps caring for those with poorer cognition and lower activity levels places increasing burden on British Indian carers, and may be implicated in provoking symptoms of anxiety and depression, at least in the short term. This did not translate into significant differences in carer strain indices between ethnic groups at final follow-up.

Carer age may also be important. Carers were significantly younger in the British Indian group, and whilst data specific to the stroke population are limited, studies in other disease cohorts report a greater risk for younger carers, from lack of personal resources, and lower levels of mutuality and rewards of meaning (Carter *et al*, 2010). We hypothesise that different losses (for example, in employment) and

challenges faced by the younger carers in the British Indian group, combined with reduced stroke survivor activity levels and poorer cognition, may contribute toward higher depressive symptomatology.

A further explanation may relate to a higher likelihood of limiting long-term illness amongst ethnic minority carers. Age-corrected rates of chronic illness are higher in minority ethnic groups than in the general population (Lowdell, 2000; Office for National Statistics, 2001; Nazroo, 2005). Coping with own poor health places additional stresses on carers, and thus may contribute toward higher levels of anxiety and depression. Results from qualitative analyses may help improve our understanding of the different experiences and challenges faced by carers that may not be reflected in quantitative assessments.

Overall, diagnosing depression and anxiety in British Indian individuals and providing acceptable support is complicated by the impact of religious, cultural and individual beliefs around psychiatric symptoms and illness perception (Carter *et al*, 2010). Healthcare professionals should be aware that British Indian carers of stroke survivors have a higher risk of anxiety and depression, particularly as the uptake of psychiatric services in this ethnic group is low (Bhui *et al*, 2003; Merrell *et al*, 2006; Stuart, 2009). Further data about the prevalence and significance of depression and anxiety in British Indian carers may help to develop and appropriately target support services.

Significant associations with increased carer strain at one month were seen with younger stroke survivor age, higher level of functional dependence (Modified Rankin Scale score) and poorer cognitive function (lower MMSE score). Greater activity levels on the FAI were associated with reduced odds of having a Hospital Anxiety and Depression subscore  $>6$ , at one month. At six months, carer age was the only significant predictor of carer strain, older age being associated with lower likelihood of carer strain. Our findings are mostly in keeping with previous studies in the stroke population reporting similar associations between patient cognition (Haley *et al*, 2009; Jen-Wen Hung *et al*, 2012), dependency (Jen-Wen Hung *et al*, 2012), and activity levels (Dennis *et al*, 1998), and increased carer strain. The Haley *et al* (2009) epidemiological study reported patient mood, cognition and difficulties with physical or personal care as the most stressful aspects of caring. Few previous studies in the stroke population have reported an association with patient or carer age (Anderson *et al*, 1995; Jen-Wen Hung *et al*, 2012). This may be a consequence of differences in ethnic make-up of study populations. The analysis of predictors of carer strain in the two ethnic groups was limited by small numbers, particularly the lower than expected recruitment rates in the British Indian group.

Several differences in stroke survivor characteristics between the two groups were observed. British Indian

stroke survivors performed fewer 'extended activities of daily living', before their stroke, and at one month, despite having similar scores to those in the White British cohort in measures of physical function, and disability (Modified Rankin Scale and Barthel Index scores). This may be due to a cultural tendency toward more reliance on informal carers in the British Indian stroke survivor cohort. An alternative hypothesis is that British Indian carers are more anxious to do everything for their relative instead of encouraging independence. Previous studies have shown that lower levels of activity are associated with increased carer strain (Iles *et al*, 2008), and we postulate that they may be a contributing factor to observed higher levels of depressive symptoms.

There was a trend toward lower scores in several of the health-related quality of life domains in both the stroke survivors and carers in the British Indian cohort, at one month and long-term follow-up. Though few of these met statistical significance, the poorer scores reported in general health, social functioning and emotional wellbeing in the British Indian cohort are important, particularly given the lower uptake of professional health and social support by ethnic minority populations (Stuart, 2009). Results from our forthcoming qualitative analyses may add to our understanding.

British Indian stroke survivors performed consistently poorer in cognitive assessments than White British counterparts, at one month and long-term follow-up. Cognitive impairment post stroke has been shown to be associated with increased carer strain both in this study and in previous reports (Anderson *et al*, 1995; Jen-Wen Hung *et al*, 2012). Failure to identify early cognitive impairment in ethnic minority populations may be due to patient and carer factors and a lack of readily available validated tools or translated material. Though the MMSE is validated in Gujarati, there are little data on its use in Punjabi. Whilst the proportion of Black and Minority Ethnic people affected by dementia in the UK is broadly similar to that found among white people (Shah, 2010), higher levels have been found in non-English-speaking groups (McCracken, 1997). Importantly, there have been no large-scale UK prevalence studies to indicate that our findings may reflect a general population difference in cognitive impairment. Notably, qualitative studies and a systematic review of the literature about dementia in the South Asian population have identified limited knowledge about this condition, its causes and potential treatments (Haworth, 2005; Turner and Purandare *et al*, 2007; Gobinderjit 2013;). South Asians are also under-represented in dementia services and mental health services in general (Bhui *et al*, 2003; Bowl 2007). Though the observed differences in cognition found in our study may in part be attributable to differences in stroke type between the groups,

or differences in educational levels, recognition of dementia symptoms is crucial to early diagnosis and treatment. Carers of stroke sufferers should be provided with clear and understandable information about the symptoms and causes of post stroke cognitive impairment and available support.

### Strengths and limitations

We studied a relatively unselected group of patients and carers, with a representative range of stroke severity and functional dependency, thus improving the generalisability of findings. We examined the role of a variety of factors affecting carer strain and were able to overcome some of the methodological shortcomings of previous studies.

The main limitation of the study was the small sample size, due to difficulties in recruitment, and a higher than expected number of participants not completing the study. Numbers in the British Indian group were lower than anticipated, and numbers of Punjabi speakers particularly small, thus not allowing comparison between Gujarati and Punjabi participants. Other limitations include: the change to follow-up period from 6 to 3 months, driven by difficulties in recruitment; exclusion of those not expected to survive >1 month, which may have led to lower recruitment rates of more severe stroke survivors; under-representation of those residing in care homes, although this was not likely to exclude British Indian stroke survivors. In addition, we can only comment on stroke survivor and carer characteristics at one and 3–6 months following stroke, and as such cannot draw conclusions on longer-term outcomes.

### Conclusions

We found no significant differences in either the incidence or predictors of carer strain between White British and British Indian carers of stroke survivors. Symptoms of depression and anxiety were more common among the British Indian cohort; carers were significantly younger. British Indian stroke survivors were more likely to have significant cognitive impairment and reported lower levels of functional activity, both of which have been associated with higher carer burden in previous studies. We cannot recommend specific population-targeted interventions to reduce carer strain from this study, and further research with a larger sample size and longer follow-up is needed. Health professionals, in both primary and secondary settings, should be aware of the increased probability of depressive symptomatology among British Indian carers of stroke survivors and its potential association with

increased carer strain. Assessment of cognition among British Indian stroke survivors should take account of the higher incidence of cognitive impairment and possible limited understanding among family members. Education for White British and British Indian stroke survivors and their families should include specific, and culturally appropriate, translated advice about dementia, depression, anxiety and cognitive impairment.

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#### CONFLICTS OF INTEREST

None.

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