Factors associated with strain in co-resident spouses of patients following stroke

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Abstract

Objective: To identify the factors associated with carer strain following stroke.

Design: Co-resident spouses of stroke patients were sent questionnaire measures of their perceptions of strain, stress, mood, handicap, adjustment, social support, life satisfaction and personality, and patient's mood and independence in activities of daily living.

Setting: Stroke spouses were identified from the stroke register at City Hospital, Nottingham.

Results: In a sample of 222 carers, 37% had significant strain. Strain was highly correlated with negative affectivity on the Positive and Negative Affectivity Scale, carer mood on the General Health Questionnaire-12 (GHQ-12) and carer's perceptions of patient's independence in activities of daily living on the Extended Activities of Daily Living Scale (EADL). Logistic regression analysis of 96 of these carers supported the correlations and showed three factors, carer GHQ-12, patient

EADL and negative affectivity, were independently associated with carer strain.

Conclusion: The relationship between these factors and strain needs to be tested prospectively. Early identification of carers who may be at risk of strain later on will enable services to be targeted at prevention rather than cure.

Introduction

Increases in life expectancy have resulted in a high proportion of elderly people in the population who require informal care. Changes in government health care policy in the UK have shifted attention from institutional to community-based care.[1] There are approximately six million carers in Britain – about 2.5 million men and 3.5 million women. Of those carers who are co-resident with the disabled, almost half spend 50 hours a week or more caring and this figure is even higher among carers aged 65 or over.[2] It is undisputed that caregivers experience significant strain.[3] Accurate identification of potential stressors, or of carers likely to be unable to cope would enable effective targeting of support to reduce carer strain and help in effectively continuing their role.[4] Carer strain can reduce the quality of care given to patients[5] and impact upon physical and psychological well-being.[6] Care for people with stroke is largely undertaken informally by friends, family or neighbours.[7] Spouses are more likely than other relatives to provide care at home[8] and have been identified as the group most at risk from strain.[9] Personal care may be required, including assistance with washing, bathing, dressing, toileting and incontinence, and physical help such as getting in and out of bed, walking and getting up and down stairs. The spouse may have to adapt to new responsibilities, changes in working life, sex life, finances, social mobility and interpersonal relationships.[10] There may be depression or anxiety,[11,12] lack of leisure time, family or marital conflict[11,13] and loss of sleep.[14] Carers express fears about the patient having another stroke, having a stroke themselves[10,12] and of their own, or their partner's death.[15]

Strain may also be related to satisfaction with their partner's progress.[3] These negative impacts of stroke may be long standing.[13]

Thompson et al.[16] found that physical impairment of the patient was an important predictor of depression amongst caregivers. Previous research showing carer strain focuses primarily on characteristics of the patients.[17,18] Research that is needed includes characteristics of the carer that may make them more susceptible to strain and psychological distress.

Cantor[9] suggested that strain is an emotionally laden factor, which is distinct from physical impact on personal life. Certain characteristics of the carer may contribute more to carer strain than environmental and situational changes, or the physical and emotional status of the patient. Particularly relevant are poor carer health and well-being[19,20] and carer depression.[10] Carers reported a deterioration in physical health after becoming caregivers.[19] Grant[20] reported a higher frequency of physician visits and use of health services in carers compared with non-caregiving samples. Significant levels of depression have been reported. Schulz et al.[12] reported depressive symptomology rates two and a half to three times higher than those of non-caregiving samples.

The provision of quantitative data collected using valid and reliable measures will help to identify carers at greatest risk of adverse emotional outcome and therefore those towards which intervention could be targeted. The overall aim of the study was to investigate factors associated with the experience of strain in a group of individuals caring for a partner who had had a stroke.

Method

Patients

All patients admitted to City and University Hospitals, Nottingham, who had had a stroke according to the WHO (1978)[21] definition were recorded on a register. The patient's name, gender, marital status and admission details were taken from this register.

Co-resident spouses of patients who were recorded consecutively between January 1995 and July 1997 were considered for inclusion in the study. Each patient's general practitioner (GP) was contacted in order to check whether the patient was alive and that their address and marital status had not changed since admission to the hospital. The carers were contacted unless the patient or carer was in hospital, residential care, had died or had moved away. The study had the approval of Nottingham City Hospital Ethics Committee.

Procedure

Two sets of questionnaires were sent to these carers. Carers were asked to return the questionnaires by post unless the carer required help with the completion of the forms, in which case home visits were made or help was provided over the telephone. Help was given reading the questions or writing the answers, but no extra information was provided, so that data from these questionnaires was comparable to those received through the post. Due to the large number of measures being used, the questionnaires were compiled into

two forms sent two weeks apart. A covering letter sent with the questionnaire assured the carers that they were under no obligation to complete the form and that not doing so would have no effect on their future care.

Reminder letters were sent to all non-returners and replacement questionnaires sent out where required.

Strain was measured using the Caregiver Strain Index (CSI)[3] as a brief and easily administered screening instrument for the identification of strain. The CSI contains 13 items related to strain (see Table 4). The scale has established reliability (alpha = 0.86) and correlates with patient characteristics, caregiver's subjective perceptions of the caregiving relationship and the physical and emotional health of the caregiver.[3] The cut- off point for strain of ≥7 was suggested by the author.[3]

Stress was measured using the Perceived Stress Scale (PSS),[22] which assesses subjective appraisals of stress as opposed to more objective measures of strain or the number of stressful events. This 14-item scale has established reliability (alpha = 0.75) and correlates with indices of depressive symptomology.[22] Carer mood and carer perceptions of patient mood were measured using the General Health Questionnaire-12 (GHQ-12)[23] to detect nonpsychotic psychiatric disorder. The London Handicap Scale[24] was used as a generic health status measure for quantifying disadvantage or 'handicap'. Patients were assessed by carers on the Extended Activities of Daily Living Scale (EADL)[25] to assess the level of perceived independence in instrumental activities of daily living in

their partners. The scale incorporates 22 activities in four subsections – mobility, domestic, kitchen and leisure. Measurement of carer characteristics included assessment of self-esteem on the Rosenberg Self- Esteem Scale,[26] to measure perceived self-worth as a personal resource.

Attributional style was assessed on the Multi- dimensional Health Locus of Control Scale.[27] The scale comprises three subscales: 'internality' measures belief in personal control over events, 'chance' measures belief in chance or external factors and 'powerful others' measures belief in the control of powerful others, in particular, health professionals. The Positive and Negative Affect Schedule (PANAS)[28] was used to assess emotional style or more enduring trait measures of affect in an individuals' predisposition to experience positive or negative mood states. Mood states include anger, disgust, scorn, guilt, fearfulness and depression, or in contrast, level of energy, excitement and enthusiasm.

Emotional control was measured using the Courtauld Emotional Control Scale (CECS)[29] to assess an individual's tendency to hide feelings versus the tendency to openly express emotions. The CECS has three subsections addressing anger, fear and depression responses. The Life Orientation Test (LOT)[30] was used to assess dispositional optimism or 'a habitual style of anticipating favourable outcomes'. The higher the score, the more strongly the individual possesses optimism as an enduring personality trait.

Carers' perceptions of their actual and ideal levels of practical and emotional

informal support from significant others was assessed on the Significant Others Scale.[31] On this scale a score was obtained for the discrepancy between actual and ideal levels of support, to provide an index of likely satisfaction with the emotional and practical support they receive. Their perception of the amount of formal support they had received was measured on a six-point scale ranging from 'none' to 'a lot'. Carer adjustment was assessed on the eight-item Acceptance of Illness Scale.[32] The scale was developed for use with patients rather than carers, and so slight alterations to the wording were made to the scale to make it more applicable. For example, 'Because of my health I miss the things I like to do most' became, 'Because of my partner's health I miss the things I like to do most'. Overall satisfaction with life was measured using the five-item Satisfaction with Life Scale (SWLS).[33]

Results

There were 1350 patients on the Stroke Register who had had a stroke between January 1995 and July 1997, of whom 465 patients had an identifiable co-resident spouse. The first questionnaire was sent to these 465 carers. Of these, 227 (49%) were returned, of which five were incomplete and 222 (48%) were available for analysis. Of these carers, 74 (33%) were men and 148 (67%) were women. Patient ages ranged from 35 to 91 years (mean 71, SD 10.34). These 222 carers were sent the second questionnaire. Of these, 97 (44%) were returned, of which one was incomplete and 96 (43%) were available for analysis. Of these carers, 30 (31%) were men and 66 (69%) were women.

Patient ages ranged from 35 to 91 years (mean 69, SD 11.16).

Of 222 respondents, 82 (37%) scored equal to or above 7 on the CSI[3] indicating significant strain. There were no significant differences between men and women carers in strain (Mann–Whitney $U = 5666$, $p = 0.84$). The distribution of scores on each measure is shown in Table 1.

As the data were predominantly ordinal, non- parametric analysis was used. Spearman's correlation coefficients were calculated between strain and each of the questionnaire measures. Results are shown in Table 2. CSI was not significantly correlated with age of the patient or time since stroke. A high level of strain was associated with low mood in the carer, low perceived mood and EADL (kitchen, domestic, leisure and mobility) in the patient and increased handicap of the carer. The CSI was not significantly related to emotional expressivity or internal or powerful others health locus of control. Strained carers had significantly lower self-esteem, decreased positive affectivity and increased negative affectivity. Increased strain was significantly related to lower levels of dispositional optimism and adjustment to the stroke. Those carers who were more strained perceived themselves as receiving significantly less actual emotional and practical support from informal sources and this was related to a greater discrepancy between their actual level of emotional and practical informal support and what they perceived to be their ideal. There was no significant relationship between CSI and ideal levels of emotional or practical support. High levels of carer strain were associated with

higher levels of support from formal services and less satisfaction with their lives.

The 15 variables that were not significantly correlated at p ″ 0.001 were removed from consideration in the following analysis to ensure that large numbers of variables weakly or not at all associated with carer strain did not reduce opportunities to find more global effects. Logistic regression with forward selection was carried out on the 96 patients for whom all variables were available with strain as the dependent variable.

The logistic regression model for strain showed that strain on the CSI was best predicted by carer mood. Other predictors of strain significant in the equation were perceived patient EADL and negative affectivity. No other variables were significant in the model. Results are shown in Table 3. The predictive equation from the logistic regression was 75% accurate in classifying carers into those who were strained and those who were not.

If each item on the Caregiver Strain Index con- tributes an equal amount to whether a carer is strained or not strained, then the distribution of yes/no answers in the 'strained' group of carers should be comparable to the distribution of yes/no answers in the 'not strained' group. Detailed analysis of the distribution of answers for each question may reveal which factors con- tribute the most to carer strain. Results are shown in Table 4.

The chi-squared test was used to test the null hypothesis that the level of strain the carer experiences is independent of yes/no answers for each item on the

CSI. Strain yes/no was cross-tabulated against each item of the CSI.

Chi-squared was significant between overall strain and disturbed sleep, inconvenience, physical strain and whether caring was confining. Overall, chi-squared was significant between strain and family changes, changes in personal plans, whether there were other demands on the carer's time, emotional adjustments, upsetting behaviour and whether or not the carer thought that their partner had changed. There was a significant chi-squared between strain and work adjustments, financial strain and whether the carer felt overwhelmed.

Chi-squared was significant for each item on the CSI. This suggests that overall strain is distributed evenly across each item of the CSI and that each item contributes to the overall level of strain experienced.

Discussion

The most important factor associated with strain experienced by the co-resident spouse caregivers of stroke patients was carer mood. These results provide support for previous research.[3] Consistent with other research,[16] a significant relation- ship was found between carer strain and level of disability of the patient in extended activities of daily living. The third strongest factor associated with strain was negative affectivity in the carer. Although correlated with low mood, negative affectivity refers to a general, enduring trait mea- sure as opposed to a transient mood state and thus may not be as amenable to change.

The logistic regression analysis indicated that the factors significantly associated with strain were independently associated and the correlations were not significant simply because they correlated with each other. The advantage of logistic regression is that it takes account of inter-dependency between variables.

The results reported here are applicable to the co-resident spouse caregivers of stroke patients. In the pilot study only 10% of the carers completed a question on age and so this was removed from the form. Although not ideal, it was assumed that the carers, as co-resident spouses, would represent a similar age distribution to the patients with whom they cohabited. Caregiver age may influence variables such as psychological and physical health outcomes.[19] However, patient age was not a significant factor in the regression equation. There were also no data available on patient incontinence, which is a factor that may affect the level of strain experienced.

Respondents needed to be literate in English to complete the assessments, which may have excluded carers from some cultural backgrounds. It was not possible, therefore, to analyse patterns of perceptions of caregiving across cultures. Furthermore, co-resident caregivers may be more motivated and positive towards caregiving than carers who are not co-resident and so the results may not be applicable to carers of other relationships and living arrangements. The response rate in the study was relatively poor and therefore the results may not represent stroke spouses as a whole. The poor response rate

resulted in a large number of measures with a relatively modest sample size. It would be useful to compare characteristics of responders with non-responders; however, this information was not available here. The non-significance of time since stroke may be a result of possible under-representation of the longer times due to exclusion of those in hospital, residential or nursing homes or those who had moved away.

The hypothesis that strain is most strongly associated with carer mood, patient disability and negative affectivity needs to be tested prospectively. Early identification of low mood in the carers might enable early identification of those carers who will cope effectively with their partner's illness and those who will experience great distress. However, it is necessary to test whether the associations identified here hold across time, in order to determine whether early identification of later strain is possible.

This may have implications for service provision. Since the majority of existing community intervention services are initiated in response to a crisis situation, such as the breakdown of physical and psychological well-being after a partner has suffered a stroke,[6] it might be feasible to target services towards prevention as opposed to cure.

Clinical messages

- Co-resident spouses of stroke patients experience significant strain on the Caregiver Strain Index (CSI).

- Strain is most strongly associated with mood, perceived patient Extended Activities of Daily Living (EADL) and negative affectivity – these factors can now be tested prospectively.

- Early identification of carers at risk of strain later on means services can be targeted at prevention rather than cure.

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Table 1 Distribution of scores for each variable (median/interquartile range)

Variable	Possible range	n	Median	IQR
Age of patient (years)	–	222	71	64–77
Days since stroke	–	222	530	248–730
London Handicap	0–100	222	68	55–81
Occupation	0–6	222	3	2–5
Orientation	0–6	222	1	1–2
Independence	0–6	222	2	1–4
Mobility	0–6	222	3	2–3
Economic self-sufficiency	0–6	222	2	2–4
Social integration	0–6	222	2	2–3
Patient EADL	0–22	222	7	3–14
Kitchen	0–5	222	3	1–5
Domestic	0–6	222	2	0–2
Mobility	0–6	222	2	0–5
Leisure	0–5	222	2	1–3
Carer GHQ-12	0–12	222	3	1–6
Patient GHQ-12	0–12	222	4	1–7
Internal HLC	6–36	96	23	19–27
Chance HLC	6–36	96	19	14–22
Powerful HLC	6–36	96	21	18–26
CECS total expressivity[a]	21–84	96	57	48–63
CECS anger[a]	7–28	96	17	14–22
CECS depression[a]	7–28	96	20	16–23
CECS fear[a]	7–28	96	940	16–21
Life orientation test	0–48	96	17	13–21
Negative affectivity[a]	10–50	96	20	14–29
Positive affectivity	10–50	96	32	26–37
Rosenberg self-esteem scale[a]	10–40	96	20	16–22
Acceptance of illness scale	8–40	222	27	21–33
Perceived stress scale[a]	0–56	96	25	18–31
Satisfaction with life scale	5–35	96	18	12–27
Support				
Actual emotional	0–7	222	6	5–7
Ideal emotional	0–7	222	7	6–7
Actual practical	0–7	222	6	4–7
Ideal practical	0–7	222	6	5–7
Emotional discrepancy[a]	0–7	222	0.2	0–0.8
Practical discrepancy[a]	0–7	222	0.3	0–2
Professional support	0–6	222	3	1–5

CECS, Courtauld Emotional Control Scale; EADL, Extended Activities of Daily Living Scale; HLC, Multidimensional Health Locus of Control.
[a] Indicates where high score is bad.

Table 2 Variable relationships with carer strain

Variable	Carer Strain Index	
	n	r^a
Age of patient	222	−0.003
Days since stroke	222	−0.03
London Handicap	222	−0.38***
Occupation	222	0.40***
Orientation	222	0.23***
Independence	222	0.28***
Mobility	222	0.36***
Economic Self-sufficiency	222	0.37***
Social integration	222	0.32***
Patient EADL	222	−0.51***
Kitchen	222	−0.47**
Domestic	222	−0.44***
Mobility	222	−0.46***
Leisure	222	−0.39***
Carer GHQ-12	222	0.51***
Patient GHQ-12	222	0.47***
Internal HLC	96	0.06
Chance HLC	96	0.21*
Powerful HLC	96	0.09
CECS total expressivity	96	0.18
CECS anger	96	0.11
CECS depression	96	0.20*
CECS fear	96	0.15
Life Orientation Test	96	−0.32***
PANAS Negative Affectivity	96	0.56***
PANAS Positive Affectivity	96	−0.26**
Self-esteem scale	96	0.28**
Acceptance of illness scale	222	−0.36***
Perceived stress scale	96	0.42***
Satisfaction with life scale	96	−0.43***
Actual emotional support	222	−0.22***
Ideal emotional support	222	−0.12
Actual practical support	222	−0.25***
Ideal practical support	222	−0.13
Emotional discrepancy	222	0.23***
Practical discrepancy	222	0.28***
Professional support	222	0.21*

EADL, Extended Activities of Daily Living Scale;
HLC, Multidimensional Health Locus of Control;
CECS, Courtauld Emotional Control Scale.
*$p < 0.05$, **$p < 0.01$, ***$p < 0.001$.

Table 3 Factors predictive of strain in co-resident spouse carers

Strain	B	SE	df	Sig	R	exp(B)
Carer GHQ-12	0.30	0.09	10.22	0.001	0.25	1.35
Patient EADL	−0.13	0.05	7.58	0.01	−0.21	0.88
Negative affectivity	0.08	0.03	5.15	0.02	0.16	1.08
Constant	−2.05	0.82	6.28			

EADL, Extended Activities of Daily Living Scale. B, unstandardized coefficient; SE, standard error; df, degrees of freedom; Sig, significance value; R, regression coefficient; exp(B), exponential (B).

Table 4 Distribution of scores on individual items of the Caregiver Strain Index

Item on CSI	Strained	Not strained	χ^2	*p*-value
Disturbed sleep				
Yes	57 (70%)	45 (32%)	29.09	<0.001
No	25 (30%)	95 (68%)		
Patient has changed				
Yes	70 (80%)	50 (36%)	51.33	<0.001
No	12 (15%)	90 (64%)		
Work adjustment				
Yes	22 (27%)	9 (6%)	17.91	<0.001
No	60 (73%)	131 (94%)		
Financial strain				
Yes	61 (74%)	29 (21%)	61.81	<0.001
No	21 (26%)	111 (79%)		
Feeling overwhelmed				
Yes	69 (84%)	40 (29%)	63.91	<0.001
No	13 (16%)	100 (71%)		
Inconvenient				
Yes	52 (63%)	24 (17%)	49.18	<0.001
No	30 (37%)	116 (83%)		
Physical strain				
Yes	45 (55%)	14 (10%)	53.37	<0.001
No	37 (45%)	126 (90%)		
Confining				
Yes	71 (87%)	33 (24%)	82.46	<0.001
No	11 (13%)	107 (76%)		
Family changes				
Yes	58 (71%)	13 (9%)	89.75	<0.001
No	24 (29%)	127 (91%)		
Changes in personal plans				
Yes	66 (81%)	44 (31%)	49.79	<0.001
No	16 (19%)	96 (69%)		
Other demands				
Yes	38 (46%)	20 (14%)	27.53	<0.001
No	44 (54%)	120 (86%)		
Emotional adjustments				
Yes	58 (71%)	21 (15%)	70.07	<0.001
No	24 (29%)	119 (85%)		
Upsetting behaviour				
Yes	63 (77%)	37 (26%)	53.07	<0.001
No	19 (23%)	103 (74%)		