

# Coping and caring: support for family caregivers of stroke survivors

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## Coping and caring: support for family caregivers of stroke survivors

**Aims and objectives.** This study examines the physical and emotional burden experienced by caregivers of stroke survivors, compared with caregivers of patients having neurological diseases.

**Background.** Stroke survivors have residual neurological impairment, which requires long-term support and care. Anxiety, depression and poor physical health are common sequelae among family caregivers of stroke survivors. There is a reasonably consistent association between patients' levels of disability and emotional state and the emotional distress of their caregivers.

**Design.** A convenience sample of 47 families was recruited: of the 47 families, 23 had a member who suffered from stroke and 24 had a member with neurological disease.

**Method.** Two interviews were conducted at three and six months after the occurrence of the index stroke or neurological disease.

**Results.** When the two groups of caregivers were compared for anxiety, depression and physical health status after care giving, the caregivers of stroke patients demonstrated higher levels of anxiety and depression than their counterparts in the neurological disease group ( $p < 0.001$ ). However, there was no significant difference in physical health status between the two groups. Educational attainment, patient group and physical and cognitive impairment of the patients were the predictors of anxiety and the depressive status of the caregivers, while their age and level of depression contributed significantly to their physical health status.

**Conclusion.** The physical and emotional well-being of two groups of family caregivers in a neurosurgical unit were compared in the caring context. The caregivers of stroke survivors are at a greater risk of developing poor physical and emotional health than the caregivers of patients having neurological diseases.

**Relevance to clinical practice.** The results illustrated that enhanced discharge planning and nurse follow-up sessions are considered essential in maintaining the well-being of the stroke caregivers and bridging the gap between the hospital and the community.

**Key words:** advanced practice, carers, chronic illness, discharge planning

## Introduction

Stroke is the third leading cause of death in Hong Kong and causes the most chronic morbidity and disability among its victims. In Hong Kong, stroke accounted for 9.4% of the total crude death rate in 2004 (Hong Kong Hospital Authority 2005). For most stroke survivors, permanent cognitive and functional impairment are common sequelae after the acute phase. Caregivers, most often spouses, daughters or daughters-in-law, may experience anxiety and depression in assuming the caregiver role. This study highlights the physical and emotional burden experienced by the stroke caregivers and suggests the need for discharge planning to meet caregivers' needs after the patient has been discharged home.

When a family member is affected by a disease that causes disability, this is considered a critical event in the life of both the person afflicted with the disease and the family. A population-based assessment on the burden of stroke on caregivers concluded that they may experience unacceptably high levels of burden, leading to isolation and exhaustion (Anderson *et al.* 1995). In 1999, Bugge *et al.* revealed that the strain on caregivers is both complex and multi-layered. Stroke caregivers were under considerable strain in the early poststroke phase and the amount of strain increased with time. There was a fairly consistent association between patients' level of disability and emotional state and the emotional distress of their caregivers (Schulz & Tompkins 1988, Martin *et al.* 1998, Reimer *et al.* 1998). Approximately 40% of the stroke caregivers reported somatic symptoms attributed to stressful, health-related care tasks (Sit *et al.* 2004). Health care professionals working in neurological units should be aware that caring for stroke victims both increases the prevailing level of stress and precipitates further stress for the caregivers. Appropriate support and care should be provided to the caregivers to enhance better coping with the difficult life situation.

Other than emotional distress, caregivers' physical health is an important concern when they are responsible for providing assistance in the basic activities of daily living for the stroke survivors. Wright *et al.*'s study (1999) reported no significant difference in physical health between those caring for stroke survivors and those caring for victims of Alzheimer's disease, although the stroke caregivers demonstrated significantly higher levels of depression than the comparison group. Other researchers found that caregivers with physical symptoms of ill health were more likely to be depressed (Tompkins *et al.* 1988). Beth and Haley (1999) advised that further research is needed to identify factors related to caregivers' physical health systematically and to determine possible measures to prevent their physical health from declining.

Most stroke caregiving studies are cross-sectional, paying little attention to the long term consequences in caregiving. A structured and systematic follow-up of caregivers' health is deemed necessary, as emotional health can be expected to decline over time in relation to patients' prolonged recovery progress (Lore *et al.* 1999). At the later stages, after stroke, the percentage of caregivers under considerable strain was clear and the proportion increased with time (Bugge *et al.* 1999). Other studies stated that the level of depression among stroke caregivers did not seem to decrease during illness trajectories (Kotila *et al.* 1998, Scholte op Reimer *et al.* 1998, Tompkins *et al.* 1988, Han & Haley 1999, Wright *et al.* 1999, Palmer & Glass 2003). Teel *et al.* (2001) commented that many of the studies do not account for changes in an individual's experience to uncover the association of caregiving experiences at different time intervals. Therefore, research is needed to track the longitudinal changes on the emotional strain of caregivers.

A review of the literature shows that most of the studies used a non-comparable design to deduct their findings. A study correlating the psychological well-being of stroke caregivers with the norm value of the general population showed that the former have a significantly poorer psychological well-being than the norm values (Warleby *et al.* 2000). Wright *et al.*'s study (1999) used healthy caregivers and caregivers of persons having Alzheimer's disease as the control groups to make comparisons in evaluating the emotional and physical health of the spouses of stroke caregivers. Kim (2001) compared the well-being of daughter caregivers with that of daughter-in-law caregivers in Korean families. An exhaustive review of the literature on caregiving has revealed a notable lack of publications focusing on evaluating the burden of stroke caregivers with the comparison group. It is recommended that comparisons with results of studies in other patient groups be made, to help explain the specific disease-related caregiving burden (Scholte op Reimer *et al.* 1998).

Given these findings, this study explores the physical and emotional health of stroke caregivers in the sociocultural context of Chinese families in Hong Kong. This study used a comparative approach with the non-stroke patient group to explain the specific disease-related caregiving burden. In contrast to the large number of cross-sectional studies in the literature, this study enabled the assessment of changes in the outcome variables in the stroke caregivers across time.

## Aim and research questions

The aim of this study is to examine the physical and emotional health of the stroke family caregivers compared

with the caregivers of patients with other, non-stroke related neurological diseases in Hong Kong.

### Research questions

- 1 Do stroke caregivers report poorer physical health than non-stroke caregivers?
- 2 Do stroke caregivers report poorer emotional health non-stroke caregivers?
- 3 Do patients' functional and cognitive status relate to caregivers' emotional and physical well-being?
- 4 Can caregivers' characteristics and patients' impairments predict caregivers' physical and emotional strain over time?

### Research method

#### Study design

The study was a descriptive, comparative study carried out in a Hong Kong hospital from March 2003 to April 2004. A cohort of caregivers of stroke patients and caregivers of patients with neurological diseases was recruited sequentially from a general regional hospital. The study only included informal caregivers (i.e. a spouse, a family member or a friend) who identified themselves as having primary responsibility for their patients. The caregivers of patients having neurological diseases comprised the comparison group. In the neurosurgical unit, the stroke patients were undergoing prolonged rehabilitation processes while other patients, such as those recovering from neurosurgical procedures, did not necessarily need lengthy rehabilitation services. For most of the stroke survivors, permanent cognitive and functional impairment are common sequelae after the acute phase. As a result, stroke caregivers suffer more demanding and stressful caregiving experiences than non-stroke caregivers. Different research instruments were used to assess these caregivers in terms of their physical and emotional health after assuming caregiving responsibilities. Face-to-face interviews were conducted in the hospital when they returned to hospital for follow-up at three months (T1) and at six months (T2) after the occurrence of the index stroke or other neurological condition. The family caregivers were excluded from the study if patients were hospitalized three months after stroke.

#### Study population

The study group consisted of caregivers of individuals who had (i) with medical evidence of haemorrhagic stroke (including subarachnoid haemorrhage), (ii) no evidence of co-existing

known malignant or other rapidly progressive medical disease and (iii) who were in-patients in the hospital's neurosurgical unit. The comparison group consisted of caregivers of individuals (i) with medical evidence of neurological diseases such as glioma, meningioma, pituitary tumour or acoustic neuroma, patients with head injuries and patients recovering from neurosurgical procedures and with functional or mobility impairment and (ii) patients with no evidence of co-existing known malignancy or other rapidly progressive medical disease. All the caregivers of these patients who were willing to participate were recruited sequentially from the department. The caregivers in the present study were Hong Kong Chinese residents with no reported history of psychiatric illness, neurological disease or cognitive impairment.

#### Assessment of patients

The patients were evaluated using two tests to determine their disabilities and cognitive status.

The cognitive status of a patient was measured using the Mini-Mental Status Examination (MMSE). The MMSE is a widely used scale with good psychometric properties. Significant cognitive impairment was defined as a score of 23 or less (Folstein *et al.* 1975). The Chinese version of the MMSE is considered reliable with Cronbach's alpha coefficient = 0.86 and test-retest reliability coefficient = 0.78. The canonical correlation coefficient = 0.94 indicated the ability to classify 94.9% of the cases in the demented group (Chiu *et al.* 1994).

Disability in the activities of daily living was measured using the Barthel Index (BI). The BI is one of the oldest and most commonly used measures in stroke research and practice. The short version, the Barthel score of 20, was used in the study (Collin *et al.* 1988). Ho and Woo (1994) suggested that the total score of 20 represents full independence in the activities of daily living, the scores of 15–19 represent mild functional disability, while scores of 14 or less represent severe functional disability. The Chinese version of the scale was validated by Sit 2001 with an inter-rater reliability coefficient of 0.99. The interpretation guidelines were also revised to become culturally specific to the Chinese population.

#### Assessment of caregivers

On the basis of a comprehensive literature review, two outcome measures were selected.

To assess caregivers' emotional health, the Hospital Anxiety and Depression Scale (HADS) was used. The scale proved to be a useful device for assessing patients' emotional state as well as for assessing the presence or

absence of clinically significant degrees of anxiety and depression. The instrument consists of two subscales; a higher score indicates a higher level of anxiety and depression (Zigmond & Snaith 1983). The Chinese version of HADS was developed by Leung *et al.* (1992). The translated version demonstrated good agreement with the English original, with good to moderate correlations among the subscales from 0.49–0.80. Cronbach's alpha coefficient for the anxiety and depression subscales was calculated and found to be 0.81 and 0.74, respectively, for the Chinese version, indicating good internal consistency.

Physical health was measured using the short form of the Multilevel Assessment Inventory (MAI), developed overseas. The MAI is an eight-item self-reported scale designed to measure general health status, with a higher score signifying better physical health. The instrument corresponds significantly with other physical health scales (Lawton *et al.* 1982). The scale was translated into Chinese by the research team and was tested in a sample of subjects. The translated version demonstrated good agreement with the English original, with good to moderate correlations among the items from 0.70–0.86. Reliability was established using the test-retest reliability method over a period of one week and the reliability coefficient was 0.95, which indicates high repeatability. The internal consistency was determined by Cronbach's alpha. The alpha coefficient was 0.83 showing high internal consistency of the scale.

Information on caregivers' demographic characteristics, which included age, sex, family income, duration of caregiving, educational background and relationship with the patients was collected during interview at T1.

### Ethical considerations

The study was approved by the Research Ethics Committees of the hospital and the university with, which the principal and the co-investigators are affiliated. The participants were asked to sign a consent form if they agreed to participate in the study. They could withdraw from the study any time during the process.

### Data analysis

Data were initially analysed using the Statistical Package for Social Sciences (SPSS), at a descriptive level. The Mann–Whitney *U*-test was used to compare the physical and emotional status of the two groups of caregivers as well as the functional and cognitive impairment of the patients. The Wilcoxon Signed Rank test was used for individual group comparisons at T1 and T2. Chi-square

tests were used to examine the relationship of the demographic variables. The Spearman's rho correlation analysis was performed to identify factors independently associated with the emotional and physical status of caregivers prior to multiple regression analysis in a staged process.

## Results

A sample of 47 families was recruited; 23 families had a member who had suffered a stroke, while 24 families comprised the comparison group. There were 47 caregivers, of which 28 were women and 19 were men.

### Caregivers' and patients' characteristics

The gender, length of caregiving, age, education, family income, employment and living conditions of the two groups of caregivers were compared and there were no significant statistical differences between the two groups except in terms of family income. The study group families were less affluent than the comparison group ( $\chi^2 = 7.648$ ,  $p < 0.05$ ). For caregivers' relationship with the patients, approximately half of the caregivers were the spouses who accounted for 54.5% and 54.2% for the study and comparison groups, respectively. Other caregiver relationships included adult children (40.9%) for the study group and parents (16.7%) for the comparison group. For the care recipients, no significant statistical differences were found in gender and age.

With regard to patients' disabilities, the mean score from the MMSE test at T1 was 9.09 and 21.29 for patients in the study and comparison groups, respectively. At T2, the scores were 9.23 and 21.54, respectively. For the measurement of functional capacity, the BI scores for the study and comparison groups were 5.91 and 15.71 at T1 and 7.23 and 15.83 at T2, respectively. The Mann–Whitney *U*-test found significant differences in the cognitive and functional status between the two groups of patients at Time 1 and Time 2 ( $p < 0.005$ ). For individual group comparisons at T1 and T2, the Wilcoxon Signed Rank test revealed significant differences in the functional status of the stroke patients over time. The characteristics of patients and caregivers are shown in Tables 1–3.

### Physical health and the prevalence of anxiety and depression among caregivers

The Mann–Whitney *U*-test showed that there was a significant difference in the level of anxiety and depression between the two groups of caregivers. The stroke caregivers had a

**Table 1** Demographic characteristics of caregivers ( $n = 47$ )

Variable	Caregivers of stroke patients ( $n = 23$ )	Caregivers of comparison patients ( $n = 24$ )	Chi-square test $p$ -value
Sex			
Male (%)	40.9	45.8	0.73
Female (%)	59.1	54.2	
Accommodation			
Public housing (%)	40.9	33.3	0.23
Private housing (%)	59.1	66.7	
Age			
Less than 50 (%)	59.0	54.2	0.45
Between 51 and 60 (%)	27.3	25.0	
Over 61 (%)	13.6	20.8	
Education			
Primary or below (%)	22.7	29.2	0.63
Secondary (%)	68.2	54.2	
Tertiary (%)	9.1	16.7	
Monthly family income			
\$5000–7000 (%)	36.4	4.2	0.02
\$7000–10 000 (%)	50.0	79.2	
> 10 000 (%)	13.6	16.7	

**Table 2** Patient characteristics

Variables	Patient with stroke	Comparison group	Chi-square test $p$ -value
Sex			
Male (%)	45.5	58.3	0.38
Female (%)	54.5	41.7	
Age			
Less than 50 (%)	31.8	41.6	0.57
Between 51 and 60 (%)	9.1	16.7	
Over 61 (%)	59.1	41.6	

higher level of anxiety and depression than their counterparts ( $p < 0.001$ ). As to physical health, the two groups showed no significant difference.

For emotional and physical status at T2, it was found that stroke caregivers continued to demonstrate a higher level of anxiety and depression six months after the index stroke, in

comparison with that of the non-stroke caregivers ( $p < 0.05$ ). Despite the huge differences in the anxiety and depression levels between the two groups of caregivers, no significant difference was found in their general physical health status. There was no significant difference in health status between the stroke caregivers and the non-stroke caregivers at both T1 and T2, even though the non-stroke caregivers had a slightly better physical health score than the non-stroke caregivers.

For individual group comparisons between T1 and T2, the Wilcoxon sign ranked test indicated that the stroke caregivers showed no significant decline in depression and anxiety over time. Similarly, the caregivers in the comparison group did not demonstrate less anxiety or depression during the course of the rehabilitation process. Both groups of caregivers had a similar level of anxiety and depression in different phases, regardless of the physical dependency and cognitive defects of

**Table 3** Functional and cognitive status of patients

	T1 mean	Three months (SD)	T2 mean	Six months (SD)	Z	$p$ -value†
MMSE						
Patient with stroke	9.09	(10.78)	9.23	(10.93)	−0.67	0.51
Patient without stroke	21.29	(9.43)	21.54	(9.77)	−0.39	0.69
$U$ , $P$ -value*	−3.40	< 0.001	−3.01	< 0.005		
Barthel Index						
Patient with stroke	5.91	(5.02)	7.23	(5.49)	−3.21	0.001
Patient without stroke	15.71	(5.13)	15.83	(5.35)	−0.38	0.71
$U$ , $P$ -value*	−4.61	< 0.001	−4.10	< 0.001		

\*Mann–Whitney  $U$ -test for between group comparisons at each time period.

†Wilcoxon sign-ranked test for within group comparisons at each time period.

the patients. There was no significant difference between the two groups in their level of physical wellness and the caregivers' physical health remained stable over time. Table 4 demonstrates the emotional and physical health status of the two groups of caregivers.

### Health status of caregivers before and after caregiving

Regarding caregivers' physical health status before and after caregiving, the caregivers were asked to indicate their self-rated physical health on a four-point Likert scale before they assumed the role of primary caregiver. The purpose was to compare this with one of the questions in the MAI on their health status at T1 and T2. For the stroke caregivers, the Wilcoxon Sign Rank test showed significant changes in the physical health status after assuming the role of family caregivers ( $p < 0.05$ ). The caregivers reported that their health was worse than one year prior to becoming the primary caregiver. The result was significant at T1 and T2 comparison ( $p < 0.05$ ). For the non-stroke caregivers, the results were similar and caregivers reported a significant decrease in the physical well being after caregiving ( $p < 0.05$ ).

### Correlations between patients' functional and cognitive status and caregivers' health

Univariate correlations were used to examine the linear relationships between patients' functional and cognitive status and caregivers' health. The Spearman's Rho correlation analysis revealed that patients' BI and MMSE were negatively correlated to caregivers' anxiety and depressive status at T1 and T2. The coefficients varied between  $-0.40$  to  $-0.55$ , indicating moderate negative correlations. There was

no significant correlation between MMSE, BI and caregivers' physical health at T1. However, there was weak to moderate negative correlation between MMSE and caregivers' physical health at T2. The results of the univariate analysis are shown in Table 5.

### Predictors of caregiver's emotional and physical health status

Based on the results of the correlation analysis in Table 5, the first analysis used caregivers' depressive status at T1 as the dependent measure. A series of multiple regression procedures was then performed to examine the contribution of selected correlating patient and caregiver variables (with  $p$ -value of 0.05 or less from the univariate analyses) on caregivers' physical and emotional health status at T1 and T2. Anxiety, depression and physical health scores were used as dependent variables for the predictions. The predictive variables including the patient group (stroke and non-stroke), MMSE and BI scores, patient's age, caregiver's age, caregiver's educational attainment and family income. Caregivers of patients with and without stroke were coded as 1 and 0, respectively, and entered into the regression model. Nominal level or categorical variables were coded using dummy coding (Munro 2001). '1' indicated that caregivers of stroke patients belonged to the chosen group. The stepwise regression model was significant (adjusted  $R^2 = 0.38$ ), with caregivers of stroke patients and caregivers' education level being the significant predictors ( $p < 0.05$ ). The second analysis used T1 caregivers' anxiety status as the dependent variable. The regression model was significant (adjusted  $R^2 = 0.53$ ) and caregivers' physical health status ( $p < 0.001$ ) and BI ( $p < 0.001$ ) were the significant predictors contributing to caregiver's anxiety status.

	T1 mean	Three months (SD)	T2 mean (SD)	Six months	Z	$p$ -value†
Anxiety (HADS)						
Stroke caregivers	7.95	(3.39)	7.86	(2.91)	-0.25	0.79
Non-stroke caregivers	4.54	(3.39)	4.83	(3.41)	-1.35	0.17
$U$ , $p$ -value*	-3.50	< 0.001	-3.15	< 0.005		
Depression (HADS)						
Stroke caregivers	9.05	(4.76)	8.91	(3.46)	-1.96	0.85
Non-stroke caregiver	3.50	(3.49)	3.58	(3.63)	-0.51	0.61
$U$ , $p$ -value*	-3.92	< 0.01	-4.15	< 0.001		
Physical health (MAI)						
Stroke caregivers	23.55	(2.97)	23.36	(2.67)	-1.17	0.24
Non-stroke caregivers	24.53	(2.40)	24.46	(2.36)	-1.13	0.26
$U$ , $p$ -value*	-1.11	0.27	-1.35	0.18		

**Table 4** Prevalence of anxiety depression and physical health among caregivers at T1 and T2

\*Mann-Whitney  $U$ -test for between group comparisons at each time period.

†Wilcoxon sign-ranked test for within group comparisons at each time period.

**Table 5** Correlations between patients' functional and cognitive status and caregivers' health

	T1 (three months)					T2 (six months)				
	Education	Income	Caregiver's age	BI	MMSE	Education	Income	Caregiver's age	BI	MMSE
Anxiety	−0.43	−0.40	NS	−0.50	−0.44	−0.45	−0.46	NS	−0.40	−0.45
Significant (2-tailed)	0.05	0.05		0.00	0.05	0.01	0.01		0.01	0.01
Depression	−0.34	−0.38	NS	−0.53	−0.41	−0.36	−0.45	NS	−0.55	−0.50
Significant (2-tailed)	0.01	0.05		0.00	0.05	0.05	0.01		0.00	0.00
Physical health	0.45	0.38	−0.52	NS	NS	0.40	0.38	−0.44	NS	0.40
Significant (2-tailed)	0.05	0.05	0.00			0.01	0.01	0.01		0.01

Spearman's rho correlations show only variables with significant correlation at the 0.05 level (2-tailed).

NS indicates non-significant.

In the following analysis, the caregivers' depression and anxiety status at T2 were used as the dependent variables. Physical health status, educational attainment and being caregivers of stroke patients were found to be the significant predictors for caregivers' anxiety status, with the adjusted  $R^2 = 0.47$ . For depression status, being caregivers of stroke patients, BI and caregivers' educational attainment were the independent predictors, with adjusted  $R^2 = 0.50$ . All the significant predictors in the model had  $p < 0.05$ .

With regard to the model on caregivers' physical health, the final analysis was derived from the physical health status

of the caregivers at T1 and T2. In both analyses, the significant predictors were caregivers' age and depressive status, with adjusted  $R^2 = 0.40$  and  $0.30$  at T1 and T2, respectively. The caregiver's age and depressive status were negatively correlated with the physical health status. The models of regression analysis are shown in Table 6.

## Discussion

This study is the first comparative study to highlight the changes in family caregivers' emotional and physical health in sub-acute and non-acute phases of stroke trajectory. The

**Table 6** Regression analyses for physical and emotional health outcomes at T1 and T2

Significant predictors	Adjusted $R^2$	Regression parameter ( $\beta$ )	$t$ -Statistics	$p$ -value	Tolerance	VIF
<b>T1 (three months)</b>						
Depression						
Caregivers group	0.38	0.57	4.90	0.000	0.99	1.002
Education level		−0.33	−2.81	0.007	0.99	1.002
Anxiety						
Physical health	0.53	−0.58	−5.75	0.000	0.99	1.004
Barthel index		−0.43	−4.18	0.000	0.99	1.004
Physical health						
Caregiver's age	0.40	−0.51	−4.38	0.000	0.94	1.07
Depression status		−0.33	−2.86	0.007	0.94	1.07
<b>T2 (six months)</b>						
Depression						
Caregivers group	0.50	0.49	4.07	0.001	0.76	1.30
Education level		−0.34	−3.21	0.003	0.98	1.02
MMSE		−0.26	−2.13	0.039	0.76	1.31
Anxiety						
Physical health	0.47	−0.33	−2.79	0.008	0.81	1.24
Caregivers group		0.40	3.58	0.001	0.94	1.06
Education level		−0.34	−2.86	0.007	0.84	1.19
Physical health						
Caregiver's age	0.30	−0.38	−3.03	0.004	0.93	1.08
Depressive status		−0.35	−2.77	0.008	0.93	1.08

VIF, variance inflation factor, the higher the VIF value, the more unstable the regression estimation.

higher level of anxiety and depression experienced by the stroke caregivers indicates the need for nurses in neurological units to provide enhanced discharge planning for this group of patients. The families need assistance in learning how to maintain their own health whilst dealing with a new and difficult life situation. This is particularly relevant for older caregivers and for caregivers who are less educated. A well designed discharge plan with continuity of care may benefit both patients and caregivers in the long term caregiving process.

### Emotional and physical health status of stroke caregivers

Our study showed that stroke caregivers experience a higher level of anxiety and depression than non-stroke caregivers during the rehabilitation phases. The borderline range of having an anxiety or depression score of 8–9 is indicative of a probable mood disorder (Zigmond & Snaith 1983). The stroke caregivers did not demonstrate many overt feelings of anxiety but suffered from a borderline depressive disorder over time. The results indicate that stroke caregivers did not appear to cope with the unexpected, caregiving role over the six month investigation period. This finding is consistent with several studies conducted on caregivers' experiences, with their risk of burnout arising from caregiving in the postacute phase of stroke (Anderson *et al.* 1995, Kotila *et al.* 1998, Scholte op Reimer *et al.* 1998, Bugge *et al.* 1999, Han & Haley 1999, Wright *et al.* 1999). The result also corroborated Thompkins *et al.*'s finding (1988) that depression during the first phase of stroke predicts depression later on. Caregivers with greater depressive symptoms soon after beginning to care for stroke survivors were more likely to be at risk for future depression.

Our findings showed no significant difference in the physical health between the two groups of caregivers during the caretaking phases. Nonetheless, the result indicated that both groups perceived their health had deteriorated as compared with a year earlier. Studies in caregivers of patients with stroke have often suggested that it is predominantly caregivers with poor physical status that are likely to have poor emotional health outcomes themselves. However, Clark *et al.* (2004) argue that family dysfunction is associated with a poorer mental health of the caregiver but not with the caregiver's physical health. Caregivers within more effectively functioning family systems are more likely to receive emotional support and less likely to feel the burden of caring for the sick family member, irrespective of their own physical health status. In addition, Draper *et al.* (1992) found no significant relationship between caregivers' self-rated health and their depression. Most of the caregivers were satisfied

with the current life situation despite the decline in physical health. The above research suggests that whilst the depressive status of the caregivers may be attributable to deterioration in their physical health, inadequate social and family support do contribute to poor psychosocial health.

### Discharge planning for the caregiving families

This study provides future directions for promoting the health of the stroke caregivers in the long rehabilitation phases. Having a high level of anxiety and depression compromises caregivers' potential and motivation to properly fulfil their caregiving role, thus affecting the way they cope with the challenges of caregiving (Bluvol & Ford-Gilboe 2004). Our results illustrated that stroke caregivers experienced significantly higher emotional distress than non-stroke caregivers at three and six months after the stroke survivor had been discharged from hospital. The caregivers' quality of life is considered an important factor in the performance of their caregiving responsibilities. Caregiving families should be given the necessary support to maintain their own physical health status and to deal with the psychosocial problems arising from their new caregiving role. Discharge planning and follow-up are necessary for all families of stroke survivors in order to identify potential emotional and physical problems before they leave the hospital and once they are back at home. Discharge planning includes four phases, namely: patient assessment, development of a discharge plan, family and patient education and follow-up evaluation (Mamon *et al.* 1992). The transitional model of care developed by Wong *et al.* (2005) summarized nursing care elements into four 'C's, namely: comprehensive assessment and planning, continuity of care, coordination of care and interdisciplinary collaboration. The provisions of transitional care to patients, alongside nurse follow-up on family caregivers, are able to stabilize family health in long-term rehabilitation. These interventions are able to provide ongoing support to improve families' capabilities in adjusting to the unexpected life events and hence reduce the physical and psychological burden on family caregivers.

### Continuity of care

The physical health of caregivers is often neglected by health care providers. Although the two groups of caregivers did not differ in the physical health status, they reported poorer health after taking up the caregiving role. During the follow-up interviews with family members, the assessment required the use of skilled nursing techniques and observations rather than solely relying on research instruments. Some minor



symptoms, such as headache, general malaise and fatigue indicate the health status and level of decline in the physical wellness of the caregivers. Caregiving is a demanding task and substantial support to alleviate physical fatigue related to caregiving is an important aspect of nursing practice. Nurses are required to extend all the support they can to the stroke patient's family, as this is an important way of achieving an optimal level of role performance. Besides working with caregivers, other interdisciplinary input includes raising community resources to enable physiotherapy and occupational therapy services at home. These services help give greater functional independence to stroke survivors and subsequently improve caregivers' physical wellness. The level of anxiety and depression of caregivers is linked to the health status of the stroke patients; only when these patients have fewer residual symptoms, will the levels of anxiety and depression of caregivers be reduced.

### Predictors of physical and emotional well being of caregivers

To determine the factors contributing to depression in stroke caregivers, a variety of caregiver and patient factors were studied as possible predictors. Previous studies demonstrated that caregivers' depressive symptoms were significantly related to patients' functional and cognitive impairment status (Palmer & Glass 2003, Sit *et al.* 2004, Anu Berg *et al.* 2005; Suh *et al.* 2005). With regard to predictions on social variables, the studies of Grant *et al.*, offered different conclusions on stroke caregivers' education and demographic characteristics in relation to depression (Grant *et al.* 2000, 2001, 2004). The most recent study (Grant *et al.* 2004) reported that the level of depression in caregivers was unrelated to their demographic characteristics. There are inconsistent findings in the literature in predicting the relationship between emotional status and demographic characteristics.

The families of stroke survivors taken as a sample in the study were less affluent than those in the comparison group. Family income, caregiver's age, educational attainment and living environment are factors that can affect caregivers' level of anxiety and depression during caregiving. Other than demographic variables, personality, social support, knowledge, activity restriction and family relationship also affect the psychosocial well-being of caregivers. Given that economic challenges and limited resources in the community may affect a caregiver's quality of life, providing financial support to the family of the stroke victim survivor could certainly relieve the immediate burden. However, nurses should be aware that providing financial assistance to stroke survivors'

families is not the ultimate solution for their long-term emotional distress. Bluvol and Ford-Gilboe (2004) stated that clinicians should consider each family and caregiver's unique experiences to design interventions that build on their strengths rather than focus on their weaknesses. In discharge planning, it is important for nurses to look into the individual family context and to help resolve family problems, if needed. The nurse is encouraged to collaborate with a medical social worker for interdisciplinary input in providing realistic support for caregivers to help them to adapt to situations that cannot be changed. An effective health programme should focus on empowering an individual or family to cope with the environment and not to remain as a passive recipient of care services (Ottawa Charter for Health Promotion 1986).

From the regression models, it is interesting to find that educational attainment of the caregivers contributed significantly to their emotional health during caregiving. Other caregiver variables, including age and depressive status also affect caregivers' physical health. In addition, the levels of patients' cognitive impairment (MMSE) were attributed to caregivers' depression. According to Clark *et al.* (2004), a higher educational attainment and the absence of major health problems in caregivers were associated with better caregiver physical health. With better education, the ability to deal with situations reflectively is improved. It also has to be noted that being better educated has a knock-on effect: higher income, better standard of living and greater likelihood of being able to pay for extra help when solving problems. In the study, caregivers having a higher educational attainment experienced less depression in both phases and less anxiety at T2. In the clinical environment, nurses need to identify the caregivers who have a low educational attainment to be able to help them improve their problem solving abilities and their coping mechanisms for unexpected life circumstances. Providing the usual general information on stroke recovery and patient care may reduce the anxiety of some clients but may not be beneficial to all caregivers as a whole. In addition, family caregivers who are less educated face problems of accessing informational support (Sit *et al.* 2004). Discharge planning with individualized care plans, effective and appropriate information transfer, outreach and community nursing services and telephone follow-ups are able to provide continuous support to caregivers' families, especially those with lower educational attainment. Telephone follow-ups serve the purpose of evaluating and reinforcing the effectiveness of health teaching that has been previously given to the caregivers.

This study also found that caregivers' age is inversely related to their physical health status. The older the caregiver,

the poorer physical health status was reported. Income and living environment contribute significantly to the physical health of caregivers. Older caregivers are at a greater risk of experiencing depression due to boredom, financial problems and role overload, thus, causing a decline in their physical wellness. In addition, older people are more vulnerable to most kinds of chronic diseases, thus, affecting their physical health. Therefore, it is important for nurses to take into account a caregiver's age when planning for discharge interventions and providing continuity of care for these elderly caregivers. PredischARGE education that includes information about food nutrition, exercise, personal hygiene and smoking is critical in maintaining the physical wellness of elderly caregivers. Regular telephone follow-up sessions involve discussions with family members about their concerns and assessment of their level of exhaustion; these will ensure the continuity of care to the family. The use of telephone-based intervention could be used as a routine practice to provide postdischarge intervention in management of psychological well being of the caregivers after hospitalization.

Finally, the patient group is a significant contributor to the anxiety and depressive status of the caregivers across time. The findings confirmed that a prolonged recovery process had a stronger psychological impact on stroke caregivers than on their counterparts. Nurses working in the neurosurgical units are advised to exert extra effort in developing a discharge plan of care for stroke caregivers. An holistic assessment and discharge plan is able to bridge the gap between the hospital and the community and it benefits both patients and caregivers in a changing healthcare delivery system.

## Conclusion

This study is limited by its small sample size. The important findings contribute to the knowledge base about understanding the physical and emotional burden of stroke caregivers as compared with that of non-stroke caregivers of patients from a neurosurgical unit. Through examining the predictors of emotional and physical distress, nurses can gain a better insight into how to develop an effective discharge plan and follow-up programme for family caregivers to improve their health. Further research is required on the effects of the discharge programme in alleviating the physical and emotional burden of stroke survivors and their caregivers' needs to be undertaken.

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## Contributions

Study design: SC, CP, FW; data collection and analysis: SC, CP; manuscript preparation: SC, FW.

## References

- Anderson GS, Linto J & Stewart-Wynne EG (1995) A population-based assessment of the impact and burden of caregiving for long-term stroke survivors. *Stroke* **26**, 843–849.
- Anu Berg L, Heikki P, Jouko L, Matti L, Lic P & Markku K (2005) Depression among caregivers of stroke survivors. *Stroke* **36**, 639–643.
- Beth H & Haley W (1999) Family caregiving for patients with stroke. *Stroke* **30**, 1479–1485.
- Bluvol A & Ford-Gilboe M (2004) Hope, health work and quality of life in families of stroke survivors. *Journal of Advanced Nursing* **48**, 322–332.
- Bugge C, Alexander H & Hagen S (1999) Stroke Patients' informal caregivers: patient, caregiver and service factors that affect caregiver strain. *Stroke* **30**, 1517–1523.
- Chiu HFK, Lee HC, Chung WS & Kwong PK (1994) Reliability and validity of the cantonese version of mini-mental state examination-a preliminary study. *Journal of Hong Kong College of Psychiatry* **4**(Suppl. 2), 25–28.
- Clark P, Dunbar S, Shields C, Viswanathan B, Aycock D & Wolf S (2004) Influence of stroke survivors characteristics and family conflict surrounding recovery on caregivers' mental and physical health. *Nursing Research* **53**, 406–413.
- Collin C, Wade D, Davis S & Horne V (1988) The Barthel ADL index: a reliability study. *International Journal of Disability Studies* **10**, 61–63.
- Draper BM, Poulos CJ, Poulos RG & Ehrlich F (1992) A comparison of care-givers for elderly stroke and dementia victims. *Journal of American Geriatric Society* **40**, 896–901.
- Folstein MF, Folstein SE & McHugh PR (1975) Mini-mental state: a practical method for grading the cognitive state of patients for the clinicians. *Journal of Psychiatric Research* **12**, 189–198.
- Grant J, Bartolucci A, Elliott T & Giger JN (2000) Sociodemographic, physical and psychosocial characteristics of depressed and non-depressed family caregivers of stroke survivors. *Brain Injury* **14**, 1089–1100.
- Grant J, Weaver M, Elliott T, Giger JN & Bartolucci A (2001) Social problem-solving abilities, social support and adjustment among family caregivers of individuals with a stroke. *Rehabilitation Psychology* **46**, 44–57.
- Grant JS, Weaver M, Elliott TR, Bartolucci AA & Giger J (2004) Family caregivers of stroke survivors: characteristics of caregivers at risk for depression. *Rehabilitation Psychology* **49**, 172–179.
- Han B & Haley W (1999) Family caregiving for patients with stroke: review and analysis. *Stroke* **30**, 1478–1485.
- Ho S & Woo J (1994) *Social and health profile of the Hong Kong old-old population*. The Chinese University of Hong Kong, Hong Kong.
- Hong Kong Hospital Authority (2005) *Epidemiological and Disease Profile*. Available at <http://www.ha.org.hk/hesd/nsapi/> (accessed 23 June 2005).

- Kim JS (2001) Daughters-in-law in Korean caregiving families. *Journal of Advanced Nursing* 36, 399–408.
- Kotila M, Numminen H, Waltimo O & Kaste M (1998) Depression after stroke: results of the finnstroke study. *Stroke* 29, 368–372.
- Lawton MP, Moss M, Fulcomer M & Kleban MH (1982) A research and service oriented multilevel assessment instrument. *Journal of Gerontology* 37, 91–99.
- Leung CM, Ho S, Kan CS, Hung CH & Chen CN (1992) Evaluation of the Chinese version of the Hospital Anxiety and Depression Scale: a cross-cultural perspective. *International Journal of Psychosomatics* 40, 29–34.
- Lore W, Hickey J, Buckwalter K, Hendrix S & Kelechi T (1999) Emotional and physical health of spouse caregivers of persons with Alzheimer's disease and stroke. *Journal of Advanced Nursing* 30, 552–563.
- Mamon J, Steinwachs D, Fahey M, Bone L, Oktay J & Klein L (1992) Impact of Hospital discharge planning on meeting patient needs after returning home. *Health Services Research* 27, 155–175.
- Martin D, O'Rourke S, Lewis S, Sharpe M & Warlow C (1998) A quantitative study of the emotional outcome of people caring for stroke survivors. *Stroke* 29, 1867–1872.
- Munro B (2001) *Statistical Methods for Health Care Research*. Lippincott, Philadelphia.
- Ottawa Charter for Health Promotion (1986) *First international conference on health promotion*. Ottawa, Canada.
- Palmer S & Glass T (2003) Family function and stroke recovery: a review. *Rehabilitation Psychology* 48, 255–265.
- Reimer WJM, de Hann RJ, Rijnders PT, Limburg M & van den Bos GAM (1998) The burden of caregiving in partners of long-term stroke survivors. *Stroke* 29, 1605–1611.
- Scholte op Reimer WJM, de Haan RJ, Pijnenborg JMA, Limburg M & van den Bos GAM (1998) Assessment of burden in partners of stroke patients with the sense of competence questionnaire. *Stroke* 29, 373–379.
- Schulz R & Tompkins C (1988) A Longitudinal study of the psychosocial impact of stroke on primary support persons. *Psychology and Aging* 3, 131–141.
- Sit J (2001) The Impact of Social Support on Perceived Well Being Of Stroke Survivors. Unpublished doctoral thesis. The Hong Kong Polytechnic University, Hong Kong.
- Sit J, Wong T, Clinton M, Li L & Fong YM (2004) Stroke care in the home: the impact of social support on the general health of family caregivers. *Journal of Clinical Nursing* 13, 816–824.
- Suh M, Kim K, Kim I, Cho N, Choi H & Noh S (2005) Caregiver's burden, depression and support as predictors of post-stroke depression. *International Journal of Nursing Studies* 42, 611–618.
- Teel C, Duncan P & Lai SM (2001) Caregiving experiences after stroke. *Nursing Research* 50, 53–60.
- Tompkins A, Schulz C & Rau M (1988) Post-stroke depression in primary support persons; predicting those at risk. *Journal of Consulting and Clinical Psychology* 56, 502–508.
- Warleby GF, Moller A & Blomstrand C (2000) Spouses of first-ever stroke patients psychological well-being in the first phase after stroke. *Stroke* 32, 1646–1651.
- Wong F, Mok M, Chan T & Tsang MW (2005) Nurse follow-up of patients with diabetes: randomized controlled trial. *Journal of Advanced Nursing* 50, 391–402.
- Wright L, Hickey J, Buckwalter K & Hendrix S (1999) Emotional and physical health of spouse caregivers of persons with Alzheimer's disease and stroke. *Journal of Advanced Nursing* 30, 552–563.
- Zigmond AS & Snaith RP (1983) The hospital anxiety and depression scale. *Acta Psychiatrica Scandinavica* 67, 361–370.