

Social support, coping strategies and health-related quality of life among primary caregivers of stroke survivors in China.

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Abstract:

Aims and objectives

To examine the relationships of social support and coping strategies to health-related quality of life among primary caregivers of stroke survivors in China.

Background

Caring for a stroke survivor is highly stressful, which can negatively affect a caregiver's physical and psychological well-being. Stroke caregivers generally report more somatic symptoms, depressive symptoms, sleep disorders and social isolation. They generally have poorer quality of life than the general population.

Design

A cross-sectional, descriptive, correlational study.

Methods

A quasi-random, point of reference sample of 121 survivor–caregiver dyads was recruited from three community health centres and six health service stations in a city in central China. Data were collected in face-to-face interviews at participants' homes using structured questionnaires.

Results

Higher educational levels, planning and active coping were positively associated with health-related quality of life. The number of chronic conditions, hours of care per day and functional dependence of the survivor were negatively related to quality of life.

Conclusion

Active coping strategies predicted better health-related quality of life. Findings suggest that intervention programmes should be developed to enhance caregivers of stroke survivors' coping skills and improve social support for these caregivers in China.

Relevance to clinical practice

Community healthcare providers may need to help caregivers strengthen strategies that are effective (planning, active coping, seeking instrumental and emotional support) and change those that are not helpful (venting, denial and self-blame).

Keywords: caregiver | coping strategies | health-related quality of life | social support | stroke survivors | China | nursing

Article:

Introduction

Stroke is a serious public health problem with high recurrence rates, disability, morbidity and mortality (Wang 2008a). Annually, 15 million people worldwide suffer from stroke, 5 million die and another 5 million experience residual disabilities (World Health Organization 2009). Stroke is a leading cause of disability in China (Zhu & Zheng 2006): approximately 70–80% of survivors manifest paralysis, speech difficulties or emotional problems (Centers of Disease Control & Prevention 2009, Ministry of Health of the People's Republic of China's 2005). Survivors typically return home after hospitalisation, where they rely on emotional and physical support from family members (e.g. spouses, adult children and siblings), close friends and sitters to aid in their recovery (Han & Haley 1999). Caring for a stroke survivor is highly stressful and can negatively affect the caregivers' physical and psychological well-being (King et al. 2001). Stroke caregivers tend to report more somatic symptoms (fatigue, headache, etc.), depressive symptoms, sleep disorders and social isolation and enjoy less life than non-caregivers (Sit et al. 2004).

Quality of life (QoL) is defined as 'individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns' (World Health Organization Quality of Life Group 1998). Health-related quality of life (HRQoL) includes health aspects of overall QoL, that is, a person's perceived physical and mental health. Examining HRQoL can identify subgroups with poor physical or mental health and thus can help guide policies or interventions to improve their health (U.S. Department of Health & Human Services 2000).

Background

Over the past several years, factors influencing HRQoL in stroke caregivers have received considerable attention in the developed world. Studies have shown that stroke caregivers have lower HRQoL than the overall population, particularly in the domains of mental health, vitality and general health (White et al. 2006). Furthermore, social support and coping strategies have been shown to be significant factors in caregivers' HRQoL (Grant et al. 2006, Ekwall et al. 2007). Personal and contextual factors, including caregivers' age, gender, educational level, health status, family income, relationship to stroke survivor, caregiving duration, hours of care per day and the stroke survivor's functional status, also influence HRQoL (McCullagh et al. 2005, Chow et al. 2007).

According to Lazarus and Folkman (1984), a person under stress first appraises the severity of the consequences of a stressor (primary assessment) and then appraises the available resources (e.g. social support) and possible coping strategies (secondary assessment). Primary and secondary assessments influence each other and determine the amount of stress experienced. Finally, the coping process refers to a person adopting a coping strategy (active or passive). The effectiveness of coping strategies influences a person's health outcome, including social functioning, mental well-being and physical health. The conceptual framework for this study was based on Lazarus and Folkman's theory and a literature review of stress results from caring for a stroke survivor with functional dependence. Predictive factors included personal characteristics of caregivers (age, gender, educational level, number of chronic conditions, relationship to stroke survivor and monthly family income), functional dependence in activities of daily living (ADLs) of the stroke survivor, caregiving contextual factors (duration of caregiving and hours of care per day), social support and coping strategies. Perceived HRQoL was the conceptualised outcome variable.

Coping strategies refer to psychological and behavioural efforts used to manage the specific external or internal demands that tax a person's resources (Lazarus 1991). Coping strategies are designed to modify the stressful circumstances and regulate the emotional distress connected to the situation (Penley et al. 2002). According to Folkman and Lazarus (1988), a person's perception of mental and physical health is related to the ways he or she evaluates and copes with the stresses of living. Positive coping strategies (e.g. seeking social support and confronting) have been shown to decrease distress and depression while improving vitality and mental well-being (Lui et al. 2005, Visser-Meily et al. 2009). Also, self-sustaining coping strategies (e.g. maintaining interests outside the caring situation) predicted better HRQoL among informal caregivers aged 75 years and over (Ekwall et al. 2007). In contrast, passive avoidant coping strategies can bring about negative emotional and psychological outcomes among stroke caregivers (McClenahan & Weinman 1998). In one study, passive coping was the most

important negative predictor of spouses' quality of life one year poststroke (Visser-Meily et al. 2005).

When demands in the environment exceed the ability to manage or cope with stress, social support may help to buffer the negative effects of stress on an individual's health (Lazarus & Folkman 1984). Caregivers satisfied with their social support experience less strain and report better mental well-being and greater vitality (van den Heuvel et al. 2001) than those without such support. Family support predicted caregivers' HRQoL at three months and one year after stroke (McCullagh et al. 2005). Also, several randomised controlled trials have concluded that support interventions, when delivered by their healthcare system, significantly improve the psychological health (Franzen-Dahlin et al. 2008) and HRQoL (Mant et al. 2000, Grant et al. 2002) of family caregivers. Therefore, family support of caregivers may play an important role in HRQoL among caregivers.

A variety of caregivers' factors have been found to be significantly associated with HRQoL. Older age and female gender were associated with declining HRQoL (White et al. 2003, Li et al. 2004, Jonsson et al. 2005). Similarly, chronic illness predicted lower HRQoL scores after controlling for other variables (Morimoto et al. 2003). Higher caregiver education was correlated with better physical (Clark et al. 2004, Dong & Geng 2008) and emotional health of the caregiver (Chow et al. 2007). In contrast, low income was associated with poorer emotional and social function of the caregiver and poorer mental and physical health (Bakas & Burgener 2002, Ekwall et al. 2007).

Greater functional dependence of the stroke survivor has also been associated with lower HRQoL scores, particularly in psychosocial domains (Sit et al. 2004, Jonsson et al. 2005, McCullagh et al. 2005). Duration of caregiving has been negatively associated with physical functioning, general health and vitality among primary caregivers (Dong & Geng 2008). Furthermore, caregivers' HRQoL scores generally have been found to be inversely proportional to the number of hours of care provided per day for stroke survivors (Kuroda et al. 2003). However, some studies have actually shown that the duration of caregiving and the daily number of hours spent caregiving had no effect on caregivers' HRQoL (Morimoto et al. 2003, Li et al. 2004).

Low HRQoL in primary caregivers may have an impact on the quality of home care that caregivers provide to stroke survivors and affects home-based rehabilitation of stroke survivors.

Accordingly, it is important for community healthcare providers to pay attention to caregivers' physical and mental health. To date, few studies have been conducted in China that have examined stroke caregivers' HRQoL or the psychosocial factors such as social support and coping strategies that affect their HRQoL,

This study therefore (1) examined social support, coping strategies and HRQoL among primary caregivers of stroke survivors in China after the survivor was discharged home; (2) examined the relationships between caregivers' age, gender, education, number of chronic conditions, relationship to stroke survivor, monthly family income, duration of caregiving, hours of care per day, survivors' functional status, social support and coping strategies and HRQoL; and (3) identified predictors of caregivers' HRQoL.

Caring for a stroke survivor with functional dependence can lead to stress. Factors predicted to impact HRQoL included personal characteristics (age, gender, educational level, number of chronic conditions, relationship to stroke survivor and monthly family income). Other potential determinants of caregivers' HRQoL included duration of caregiving and hours per day (contextual factors), social support and coping strategies. The functional dependence of the stroke survivor measured by the activities of daily living (ADLs) also was expected to be an important factor influencing caregivers' HRQoL. The primary study outcome was perceived caregivers' HRQoL.

Methods

Design

A cross-sectional, descriptive, correlational design was used in this study.

Participants

A quasi-random, point of reference sample was obtained from three community health centres and six health service stations in a city in central China. Participants included stroke survivors and their primary caregivers. Stroke survivors had a diagnosis of ischaemic including transient ischaemic attack or haemorrhagic stroke documented by computed tomographic scan or clinical examination. The survivors had been discharged home and relied on help and support from others and had no aphasia or unconsciousness.

The primary caregiver was defined as the person spending the most time in providing daily care for the stroke survivor or the person taking on the main caregiving tasks (Wang & Jiang 2007, Wang & Chen 2009). Relationship of the caregivers to the stroke survivor included the spouse, adult children, siblings, other relatives, friends and sitters. Eligible primary caregivers had taken care of the stroke survivor for at least 4 weeks, were 18 years of age or older, willing to participate in the study and were able to communicate verbally in Mandarin. Caregivers were excluded if they had a diagnosis of mental health problems or terminal illnesses; had a history of substance abuse or were not oriented to time, place or person; or were known to have dementia.

Based on an a priori power analysis, a sample of 104 survivor–caregiver dyads had sufficient statistical power (80%) to detect $R^2 \geq 0.15$ at the $\alpha = 0.05$ level of statistical significance, assuming a regression model with 11 independent variables (Polit & Beck 2004). One hundred and forty-two dyads met the study criteria, and 16 refused to participate because they were ‘too busy’ or had ‘no interest’, and five did not finish the questionnaires. The final analysis consisted of 121 dyads (Fig. 1).

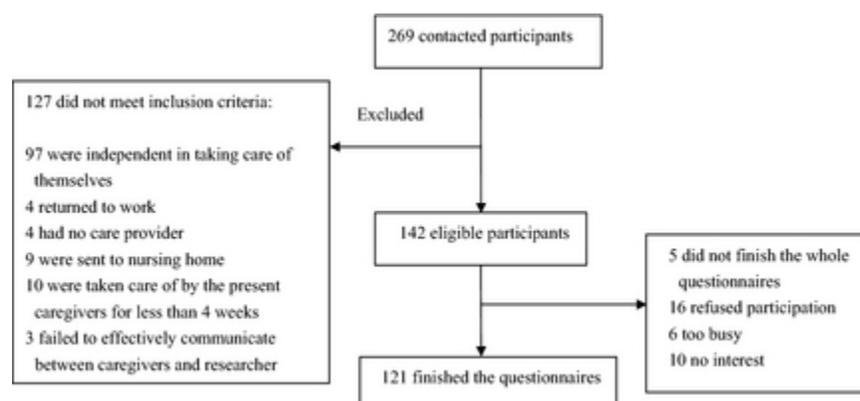


Figure 1. Flow of the process of sample recruitment.

Ethical consideration

The study was approved by the university and community health centres/stations in which the study was conducted.

Procedure and data collection

Data were collected between July and September 2009 using structured questionnaires and face-to-face interviews with participants. The first author reviewed the health files of potential participants and contacted those who were eligible for the study by telephone. The purpose of the

study was explained to potential participants, and they were informed that their involvement was completely voluntary and they had the right to refuse to participate or withdraw from the study at any time. Participants were also assured that their identities would be protected and that their study information would be held in confidence. After informed consent was obtained, the study questionnaires were administered at a mutually convenient time. Approximately 45–50 minutes was required to complete the questionnaire. To avoid introducing bias, the researcher discussed specific items but did not provide further explanation. Health-related medical information was checked by reviewing the patient's health file.

Instruments

Demographic information was collected based on a literature review and the study objectives. Caregivers were asked about their age, gender, educational level, monthly family income, relationship to the stroke survivor, number of chronic conditions, duration of caregiving and hours of care per day.

Functional status

The 10-item Barthel Index (BI) (Mahoney & Barthel 1965) was used to measure functional dependence using the ten activities of daily living measure of the stroke survivor. The BI was scored in steps of 5 points, giving a maximum total score of 100. A score between 0–20 indicated total dependence, 21–40 indicated severe dependence, 41–60 indicated moderate dependence, more than 60 indicated slight dependence and a score of 100 indicated independence (Wang 2008b). The BI has been frequently used in stroke research and practice and has demonstrated good reliability and validity (Wolfe et al. 1991).

Social support

The Multidimensional Scale of Perceived Social Support (MSPSS), developed by Zimet et al. (1988), was used to measure social support from family, friends and significant others. This 12-item, self-report scale has three subscales, each with 4 items. The tool uses a seven-point Likert-type scale, where responses range from 1 ('very strongly disagree') to 7 ('very strongly agree'). Higher scores indicate higher levels of perceived social support. Each subscale is summed and divided by four, and all the items are summed and divided by 12 to provide the total score. Internal reliability coefficients were 0.87, 0.85 and 0.91 for the three subscales and 0.88 for the whole scale (Zimet et al. 1988), and test–retest reliabilities were 0.85, 0.75 and 0.72 for the three subscales and 0.85 for the whole scale (Zimet et al. 1988). The Chinese version of the MSPSS has demonstrated good reliability in previous studies (Chou 2000, Ding et al. 2008). In this

study, Cronbach's alpha estimates were 0.89, 0.96 and 0.90 for the three subscales and 0.87 for the whole scale.

Coping strategies

The Brief COPE Inventory (BCI), developed by Carver (1997), was used to assess ways of coping that might be used to deal with stressful events. This self-report questionnaire has 28 items and 14 subscales that assess particular ways of coping (two items per scale). The BCI uses a four-point Likert-type scale with ratings from 1 ('I haven't been doing this at all') to 4 ('I have been doing this a lot'). The score on each coping strategy range from 2–8 (Carver 1997). Carver (1997) found that Cronbach's alpha for the subscales ranged from 0.50 (venting) to 0.90 (substance use). Carver (1997) also reported evidence supporting the factorial validity of the BCI. The BCI has been used with Chinese caregivers of hospitalised stroke survivors and has shown satisfactory internal consistency (Cronbach's alpha = 0.83) (Qiu & Li 2008). The reliability of the scale in this study was 0.66. Several items were not included in the analysis because of low inter-item and item-to-total correlations.

Health-related quality of life

The SF-36 (Ware & Sherbourne 1992) was used to measure caregivers' HRQoL. The SF-36 is a well-known generic HRQoL instrument that includes eight subscales and 36 questions measuring physical functioning, role physical, bodily pain, general health, vitality, social functioning, role emotional and mental health. The items on the SF-36 subscales can be aggregated into two summary scales: the physical component summary (PCS) and the mental component summary (MCS) (Ware et al. 1994). These summary scales are standardised with a mean of 50 and a standard deviation (SD) of 10. Scores range from 0–100 for each subscale, with higher scores indicating better HRQoL. The SF-36 has been used with a variety of populations and has demonstrated good internal consistency reliability (alpha = 0.78–0.93), test–retest reliability (ICC = 0.76–0.93) and construct validity (McHorney et al. 1994, 1993, Ware 2000). A Chinese version of the SF-36 has demonstrated good reliability and construct validity, with Cronbach's alpha coefficients of 0.90 for the PCS scale and 0.91 for the MCS scale (Li & Wang 2009, Qiu et al. 2012). In this study, Cronbach's alpha coefficients were 0.90 for the PCS scale and 0.91 for the MCS scale.

The BI scale and the BCI scale were written in English and required translation into Chinese, which was then translated back into English. The back-translated version was checked against the original English version by a native English speaker prior to use in this study.

Analysis

Descriptive statistics were used to describe the characteristics of the sample and their responses to the instruments. A multivariable linear regression model was used to identify predictors of caregivers' HRQoL. Predictive variables with nominal scales were dummy coded as 0/1 variables. Separate models were computed for PCS and MCS, respectively. Model assumptions were assessed with a residual analysis. Co-linearity diagnostics were checked using VIFs and eigenanalysis. All co-linearity diagnostics indicated that there was no evidence of co-linearity. Statistical analyses were performed using sas, version 9.2 (SAS Institute Inc., Cary, NC, USA) and spss, version 17 (SPSS Inc., Chicago, IL, USA). A value of $p < 0.05$ (two-tailed) was considered statistically significant.

Results

Sample characteristics

The average age of the stroke survivors was 72.09 years (SD = 8.37) (Table 1). Most were men (62%, $n = 75$) and had only a junior middle school education or less (72.7%, $n = 88$). They did, however, have medical insurance (82.6%, $n = 100$); 69.4% ($n = 84$) reported a cerebral infraction, while 64.5% ($n = 78$) had a first stroke. Nearly all stroke survivors suffered from one to six other chronic diseases [e.g. hypertension (94.1%), heart disease (33.9%) and diabetes mellitus (22.3%)] as well as complications such as dementia, epilepsy or lung infection. The mean BI score of the survivors was 65.50 (SD = 35.97). Approximately one-third of the survivors (32.2%) were able to perform activities of daily living independently, but 26.8% were totally dependent, 14.6% were severely dependent, while 18.3% were moderately dependent and 40.3% were slightly dependent.

Table 1. Characteristics of stroke survivors and caregivers ($n = 121$)

Stroke survivors	<i>n</i>	%	Mean	SD	Range
Age (years)			72.09	8.37	45–91
45–64 (middle-aged)	18	14.9			

Stroke survivors	<i>n</i>	%	Mean	SD	Range
65–74 (young-old)	50	41.3			
75–84 (old-old)	48	39.7			
85–91 (very old)	5	4.1			
Gender					
Male	75	62.0			
Female	46	38.0			
Educational level					
No formally educated	23	19.0			
Primary school (1–6 years)	37	30.6			
Junior middle school (7–9 years)	28	23.1			
Senior middle school (10–12 years)	20	16.5			
College or above (>12 years)	13	10.8			
Marital status					
Married	101	83.5			
Divorced	3	2.5			
Widowed	17	14.0			
Types of payment					
Free medical care	14	11.6			
Insurance	100	82.6			
By oneself	7	5.8			

Stroke survivors	<i>n</i>	<i>%</i>	Mean	SD	Range
Types of stroke					
Cerebral infarction	84	69.4			
Intracerebral haemorrhage	26	21.5			
Cerebral infarction and intracerebral haemorrhage	11	9.1			
Duration since stroke (months)					
			98.71	74.83	1.5–384
≤12 (1 years)	10	8.3			
13–60 (5 years)	38	31.4			
61–120 (10 years)	35	28.9			
≥121 (more than 10 years)	38	31.4			
Times of stroke					
1	78	64.5			
≥2	43	35.5			
Length of discharge (months)					
			69.43	57.76	1–258
≤12 (1 years)	16	13.2			
13–60 (5 years)	49	42.2			
61–120 (10 years)	35	27.2			
≥121 (more than 10 years)	21	17.4			
Number of complications					
≤1	31	25.6			
2	47	38.8			

Stroke survivors	<i>n</i>	%	Mean	SD	Range
≥ 3	43	35.6			
Total score of BI			65.50	35.97	0–100
Functional status					
Independence (100)	39	32.2			
Levels of dependence					
Total dependence (0~20)	22	26.8			
Severe dependence (21~40)	12	14.6			
Moderate dependence (41~60)	15	18.3			
Slight dependence (61~95)	33	40.3			

Caregivers	<i>n</i>	%	Mean	SD	Range
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1. SD, standard deviation; BI, Barthel Index; RMB, Renminbi. * $n = 118$.

Age (years)			61.14	10.79	32–82
≤ 45	5	4.1			
46–64	38	31.4			
≥ 65	78	64.5			
Gender					
Male	33	27.3			
Female	88	72.7			
Marital status					
Single	1	0.8			

Caregivers	<i>n</i>	%	Mean	SD	Range
Married	110	90.9			
Divorced	2	1.7			
Widowed	8	6.6			
Educational level					
No formally educated	22	18.2			
Primary school (1–6 years)	25	20.7			
Junior middle school (7–9 years)	42	34.7			
Senior middle school (10–12 years)	26	21.5			
College or above (>12 years)	6	4.9			
Working status					
Unemployed	5	4.1			
Retired	101	83.5			
Work	2	1.7			
Other	13	10.7			
Monthly family income (RMB)*			2549.9	1059.1	750–5500
<2000	23	19.5			
2000–3000	72	61.0			
>3000	23	19.5			
Relationship to stroke survivor					
Spouse	96	79.3			
Adult children	15	12.4			

Caregivers	<i>n</i>	%	Mean	SD	Range
Nanny	10	8.3			
Number of chronic conditions					
0	40	33.1			
1	38	31.4			
2	30	24.8			
≥3	13	10.7			
Religious belief					
No	104	86.0			
Buddhism	9	7.4			
Christian	8	6.6			
Hours of care per day			10.97	8.77	1.5–24
Less than two hours	1	0.8			
Two to four hours	45	36.4			
Four to eight hours	13	10.7			
More than eight hours	62	52.1			
Duration of caregiving (months)			81.88	69.30	1–312
1–12 (1 years)	16	13.2			
13–36 (3 years)	27	19.9			
37–60 (5 years)	17	16.5			
61–120 (10 years)	32	26.4			
≥121 (more than 10 years)	29	24.0			

The caregivers' mean age was 66.14 years (SD = 10.79) (Table 1). The majority were women (72.7%), happened to be the care recipient's spouse (79.3%) and were retired (83.5%). Almost three-fourths (73.6%) had less than a senior middle school education, and 61% had a monthly family income of 2000–3000 renminbi (RMB) (\$300–\$450). Approximately two-thirds of caregivers (66.9%) suffered from one or more chronic conditions. The most common chronic conditions were hypertension (70.4%), heart disease (33.3%), bone and joint disease (16%) and diabetes mellitus (12.3%). Over half (52.1%) of the caregivers spent more than 8 hours a day providing care to the stroke survivor. Nearly 70% had been caregiving for more than 3 years, and the average duration of caregiving was approximately 6.8 years.

Levels of HRQoL, perceived social support and coping strategies

The mean scores on the PCS and the MCS were 69.74 (SD = 20.63) and 67.49 (SD = 20.59), respectively (Table 2). Among the eight subscales of the SF-36, the lowest mean scores were on social functioning (51.03, SD = 41.35), followed by general health (53.61, SD = 23.57) and vitality (64.83, SD = 23.88). The highest mean subscale scores were on role emotional (87.33, SD = 22.41), followed by physical functioning (78.55, SD = 17.52). The mean score on perceived social support was 4.18 (SD = 1.27), with support from friends being the scored lowest score (2.76, SD = 2.05). The mean scores for the four most common coping strategies used by stroke caregivers were acceptance (7.74, SD = 0.56), active coping (7.21, SD = 1.05), positive reframing (6.34, SD = 1.70) and planning (5.76, SD = 1.75).

Table 2. Mean and SD of the HRQoL, perceived social support and coping strategies of caregivers (n = 121)

Measure	Possible range	Observed range	Mean	SD
HRQoL				
Physical component summary (PCS)	0–100	15.19–99.25	69.74	20.63
Mental component summary (MCS)	0–100	20.25–94.50	67.49	20.59
Physical functioning (PF)	0–100	20.00–100.0	78.55	17.52
Role physical (RP)	0–100	0.00–100.0	73.86	30.57
Bodily pain (BP)	0–100	0.00–100.0	72.94	28.48

Measure	Possible range	Observed range	Mean	SD
General health (GH)	0–100	0·00–97·00	53·61	23·57
Vitality (VT)	0–100	10·00–90·00	64·83	23·88
Social functioning (SF)	0–100	12·50–100·0	51·03	41·35
Role emotional (RE)	0–100	25·00–100·0	87·33	22·41
Mental health (MH)	0–100	16·00–88·00	66·78	19·45
Social support				
From family	1–7	1·00–7·00	5·59	1·44
From friends	1–7	1·00–7·00	2·76	2·05
From significant other	1–7	1·00–7·00	4·18	1·85
Total scale	1–7	1·25–6·67	4·18	1·27
Coping strategies				
Acceptance	2–8	5·00–8·00	7·74	0·56
Active coping	2–8	3·00–8·00	7·21	1·05
Positive reframing	2–8	2·00–8·00	6·34	1·70
Planning	2–8	2·00–8·00	5·76	1·75
Self-distraction	2–8	2·00–8·00	4·74	1·72
Denial	2–8	2·00–8·00	4·34	1·26
Use of instrument support	2–8	2·00–8·00	4·11	1·41
Use of emotional support	2–8	2·00–8·00	3·86	1·56
Humour	2–8	2·00–6·00	3·52	1·32

Measure	Possible range	Observed range	Mean	SD
Venting	2–8	2.00–7.00	3.48	1.21
Self-blame	2–8	2.00–8.00	2.98	1.34
Religion	2–8	2.00–8.00	2.70	1.70
Behavioural disengagement	2–8	2.00–8.00	2.42	0.96
Substance use	2–8	2.00–8.00	2.38	1.19

HRQoL, health-related quality of life; SD, standard deviation.

Relationships between independent variables and HRQoL

The PCS scores were positively associated with caregivers' educational level ($r = 0.197$, $p < 0.05$) and negatively associated with number of chronic conditions ($r = -0.453$, $p < 0.001$) and relationship to stroke survivor ($r = -0.284$, $p < 0.01$). The MCS was positively associated with active coping ($r = 0.186$, $p < 0.05$), planning ($r = 0.286$, $p < 0.01$) and caregivers' educational level ($r = 0.243$, $p < 0.01$). The MCS scores were also correlated with BI scores of stroke survivors ($r = 0.399$, $p < 0.001$), indicating that functional independence was related to a high MCS score. The MCS scores were negatively associated with hours of care per day ($r = -0.376$, $p < 0.001$) and number of caregivers' chronic conditions ($r = -0.22$, $p < 0.05$).

Predictors of caregivers' HRQoL

PCS and MCS scores were the dependent variables in the multiple regression models, adjusting for personal characteristics of caregivers (caregivers' educational level, number of chronic conditions, relationship to stroke survivor, hours of care per day), survivors' functional status, perceived social support and coping strategies.

When caregivers' educational level, number of chronic conditions, relationship to stroke survivor, hours of care per day and stroke survivors' functional status (BI score) were entered into the model (step 1), 25.8% of the variance in the PCS was explained [$F(5, 115) = 8.013$, $P < 0.001$]. Controlling for the effects of these personal characteristics of caregivers and survivors' functional status in step 2, the combination of perceived social support and coping strategies did not substantially explain any additional variance in the PCS. With all variables in the model, 36.7% of the variance in the PCS was explained [$F(16, 104) = 3.768$, $p < 0.001$]. The number of

chronic conditions and the relationship to stroke survivor were the strongest predictors of the PCS score (Table 3).

Table 3. Hierarchical multiple regression analysis: variables predicting the PCS and MCS of HRQoL (*n* = 121)

PCS regression	β	b	SE
Step 1 ^a			
Education	0.182*	8.481	3.770
Relationship	-0.157	-11.717	6.409
Chronic conditions	-0.404***	-7.829	1.633
Hours of care per day	0.010	0.022	0.318
BI score	0.081	0.047	0.077
Step 2 ^b			
Education	0.155	7.213	4.009
Relationship ^c	-0.294**	-21.919	7.102
Chronic conditions	-0.326***	-6.324	1.736
Hours of care per day	-0.037	-0.087	0.321
BI score	0.017	0.010	0.078
Social support	0.044	0.710	1.700
Denial	-0.039	-1.944	4.671
Active coping	-0.007	-0.167	2.630
Venting	-0.198	-5.189	3.261
Self-blame	-0.153	-4.449	2.599

PCS regression	β	b	SE
Self-distraction	0.047	0.564	1.070
Emotional support	-0.087	-1.154	1.675
Instrumental support	0.164	2.393	1.393
Positive reframing	0.036	0.436	1.077
Planning	0.094	1.113	1.369
Humour	0.090	1.416	1.414
<hr/>			
MCS regression	β	b	SE
<hr/>			
Step 1 ^d			
Education	0.196*	9.126	3.772
Relationship	-0.043	-3.193	6.412
Chronic conditions	-0.203*	-3.923	1.634
Hours of care per day	-0.131	-0.308	0.318
BI score	0.301*	0.172	0.077
Step 2 ^e			
Education	0.135	6.292	3.936
Relationship ^c	-0.148	-11.016	6.971
Chronic conditions	-0.155	-2.992	1.704
Hours of care per day	-0.232	-0.545	0.315
BI score	0.205	0.118	0.076

MCS regression	β	b	SE
Social support	-0.046	-0.741	1.668
Denial	-0.029	-1.431	4.585
Active coping	0.857	-0.465	2.582
Venting	0.068	-5.906	3.201
Self-blame	-0.163	-4.737	2.552
Self-distraction	-0.086	-1.023	1.050
Emotional support	0.120	1.592	1.645
Instrumental support	0.125	1.827	1.367
Positive reframing	-0.071	-0.858	1.057
Planning	0.248*	2.920	1.344
Humour	0.152	2.381	1.388

HRQoL, health-related quality of life; PCS, physical component summary; MCS, mental component summary.

* $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$. β is standardised regression coefficient; b is unstandardised coefficient.

a PCS regression step 1: $R^2 = 0.258$, adjusted $R^2 = 0.226$, R^2 increase = 0.258 , F change = 8.013 ($p < 0.001$), $F = 8.013$ ($p < 0.001$).

b PCS regression step 2: $R^2 = 0.367$, adjusted $R^2 = 0.270$, R^2 increase = 0.109 , F change = 1.622 ($p \geq 0.05$), $F = 8.013$ ($p < 0.001$);

c Relationship: 0 = non-family caregiver, 1 = family caregiver.

d MCS regression step 1: $R^2 = 0.255$, adjusted $R^2 = 0.222$, R^2 increase = 0.255 , F change = 7.856 ($p < 0.001$), $F = 7.856$ ($p < 0.001$).

e MCS regression step 2: $R^2 = 0.387$, adjusted $R^2 = 0.293$, R^2 increase = 0.133 , F change = 2.015 ($p < 0.05$), $F = 4.111$ ($p < 0.001$).

For MCS, when caregivers' educational level, number of chronic conditions, relationship to stroke survivor, hours of care per day and stroke survivors' functional status (BI score) were entered into the model (step 1), 25.5% of the variance in the MCS was explained [$F(5, 115) = 7.856, p < 0.001$]. Controlling for the effects of these personal characteristics of caregivers and survivors' functional status in step 2, the combination of perceived social support and coping strategies contributed an additional 13.3% to the explained variance [$F(11, 104) = 2.051, p < 0.05$]. With all variables in the model, 38.7% of the variance in the MCS scores was explained [$F(16, 104) = 4.111, p < 0.001$]. However, only the coping strategy of planning significantly predicted MCS scores (Table 3).

Discussion

Levels of HRQoL, perceived social support and coping strategies

Stroke caregivers' HRQoL scores in this study were lower than those of the Chinese population (Li et al. 2003, 2001, Wang et al. 2008), except for role emotional scores (RE). Unlike other stroke caregivers studied (Jonsson et al. 2005, Morimoto et al. 2003, White et al. 2003), caregivers in this study scored very low on the social functioning subscale, suggesting that their social life had suffered severe restrictions due to caregiving. This can be explained by the fact that 52.1% of the caregivers spent more than 8 hours in caregiving daily and 86.8% had served as a caregiver for over a year. The caregiving role often takes a great amount of time and energy and is frequently characterised by reduced individual freedom and an increased sense of responsibility, both of which have consequences for caregivers' lives (Ohman & Soderberg 2004).

Stroke caregivers also perceived insufficient social support, especially from friends and other members of their social network. The support they perceived came mainly from family members and their neighbours. This may be because most of the caregivers were more than 65 years old, as were their friends. Thus, the caregivers had few close friends who could help them, because of their friends' age or because their friends had died. Also, caregivers were separated from others by the responsibilities of caregiving.

The most frequent coping strategies employed by caregivers in this study were acceptance, active coping, positive reframing and planning. Consistent with previous findings, these results suggest that Chinese caregivers use positive strategies to cope with the stress of caregiving (Kim & Knight 2008, Qiu & Li 2008).

Relationships between hypothesised predictors and HRQoL

Higher educational level was associated with better HRQoL, as in previous studies (Clark et al. 2004, Dong & Geng 2008). Caregivers with more education have more access to informational support and greater knowledge about stroke care (Sit et al. 2004). These factors may contribute to a lower threat appraisal, more effective problem-solving skills and quicker adaptation to the caregiving role.

Greater functional dependence of the stroke survivor was associated with lower HRQoL scores on the MCS for caregivers. This finding is congruent with the findings by Jonsson et al. (2005) that the functional dependence (BI score) of the stroke survivor was the most important determinant of the mental HRQoL of caregivers at 4 and 16 months poststroke. Sit et al. (2004) also found that family caregivers who looked after stroke relatives with more dependence in ADLs had poorer psychosocial health. In this study, 67.8% of stroke survivors had some disability in ADLs, which may have increased caregivers' burden and contributed to lower caregiver perception of mental health. Also, caregiving time spent per day was strongly negatively associated with mental HRQoL of caregivers. Over half of the caregivers spent more than 8 hours a day looking after their stroke survivor, which reduced the time they had to care for their own health. It also allowed them less time to socialise with friends and family members, to engage in personal hobbies or to participate in other activities. Together, this could have resulted in diminished quality of life.

Caregivers' HRQoL was not significantly associated with their age or gender. In Chinese culture, children, regardless of age, assume primary caregiving roles as part of a moral and social commitment as well as filial responsibility; thus, age might not be a determinant of HRQoL as found in other studies (McCullagh et al. 2005). Neither monthly family income nor duration of caregiving was significantly correlated with caregivers' HRQoL in this study. This might be explained in part by the majority of the stroke survivors having medical insurance (82.6%) or free medical care (11.6%). In addition, most families (80.5%) had an income of 2000–5500 RMB per month, and most caregivers had a mid-level socio-economic status. Also, the average caregiving duration was more than 3 years (66.9%), and thus, it is possible that most caregivers had become adjusted to the caregiving role and had integrated this into their normal pattern of living.

Unlike a number of studies which found that social support had a positive impact on caregivers' HRQoL (Bluvol & Ford-Gilboe 2004, McCullagh et al. 2005, Grant et al. 2006), the current study did not find perceived social support to be significantly associated with caregivers' HRQoL. This finding may indicate that less social support is available from family and friends or other resources for Chinese caregivers.

Problem-focused coping strategies, active coping and planning were positively associated with the mental health of caregivers. In other studies, caregivers who used more active coping strategies experienced less stress and depression and had better well-being and vitality (Forsberg-Warleby et al. 2004, Rochette et al. 2007). However, no coping strategy in this study was significantly correlated with the physical health of HRQoL, indicating that coping primarily influenced mental health of the caregivers.

Predictors of caregivers' HRQoL

In relation to stroke survivors, the number of chronic conditions and the coping strategy of planning predicted caregivers' HRQoL. In contrast, the relationship to the stroke survivor negatively predicted caregivers' HRQoL on the PCS, and family caregivers had poorer physical health than non-family caregivers. Also, chronic conditions were negatively associated with the mental health of stroke caregivers, which is consistent with the findings of previous studies (Morimoto et al. 2003, White et al. 2003).

Not surprisingly, the coping strategy of planning positively predicted caregivers' HRQoL on the MCS. Presumably, active coping strategies contribute to better HRQoL, and it is congruent with the finding of van den Heuvel et al. (2001) that caregivers who frequently used the positive coping strategy of confronting experienced less strain, better mental well-being, as well as greater vitality.

Study limitations

Several factors may have affected the results of this study and should be considered when interpreting the results. Sampling from only three communities may have limited the generalisability of the findings of this study. Furthermore, the use of a cross-sectional design did not allow examination of causal relationships. The Brief COPE Inventory (BCI) might not have been culturally sensitive to caregivers in China because it was originally developed in a Western

culture. Finally, questionnaires were administered in face-to-face interviews, which could have affected participants' responses to interview questions through social desirability.

Conclusion

Despite its limitations, this study contributes to additional knowledge about social support, coping strategies and HRQoL among primary caregivers of stroke survivors living at home in China. The results showed that stroke caregivers in China perceived a moderate level of HRQoL and insufficient social support, especially from other members (including healthcare providers) of their social network. Unlike other international studies of stroke caregivers, Chinese caregivers scored markedly low on the social functioning subscale. These caregivers in China face stress, burden, psychological problems and social isolation when providing care to stroke survivors. Furthermore, caregivers are often ignored by healthcare providers because most care and treatments are provided to the patients with stroke instead of caregivers. In addition, nursing care in China is primarily focused on physiological care to clients, and the psychosocial problems of patients and their family members are usually not emphasised in practice. This study also found that stroke caregivers who had lower education, more chronic diseases and looked after a stroke survivor with higher functional dependence, as well as those who were family member as primary caregivers, may have poorer HRQoL. To the contrary, those caregivers who employed problem-focused coping strategies (active coping and planning) may have better HRQoL on the MCS. Thus, this study suggests that it is important to provide emotional and informational support to caregivers of stroke survivors who have chronic conditions, less education and whose stroke survivors have more severe physical limitations. The findings also indicate that healthcare providers need to assess caregivers' physical and mental health and make appropriate interventions, providing social support and teaching positive coping skills, to promote caregivers' health and quality of life.

Relevance to clinical practice

Because the active coping strategy of planning positively predicted caregivers' HRQoL on the MCS, community healthcare providers may need to help caregivers strengthen coping strategies that are effective (planning, active coping, seeking instrumental and emotional support) or change those that are not helpful (venting, denial, self-blame, etc.). Wu and Mok (2006) found that perceived social support was more effective in maintaining the mental health than received social support. It may be helpful to enhance caregivers' knowledge and perceived competence in

caring for stroke survivors and to help them learn how to seek support and use the resources available in the form of professional-led educational sessions, group or home visiting support programmes and individualised counselling services. In addition, caregivers need to be taught positive coping skills before their stroke survivor is discharged home.

Contributions

Study design: YY, JH; data collection and analysis: YY, JH, JTE, TPM and manuscript preparation: YY, JH, JTE, TPM.

Conflict of interest

The authors have no conflict of interest.

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