ORIGINAL ARTICLE

PREDICTORS OF LIFE SATISFACTION AMONG FAMILY CAREGIVERS OF HOSPITALIZED FIRST-EVER STROKE PATIENTS IN KELANTAN

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Abstract

Objective: **The involvement of families in assisting health professionals in providing care for their family members who suffer a stroke during hospitalization is common in Malaysia. Family caregivers are accountable in providing for the first-ever stroke survivor's needs, including maintaining functional improvements gained in rehabilitation and the long-term well-being of the stroke survivors. The objective of this study was to determine the predictors of life satisfaction among family caregivers of hospitalized first-ever stroke patients.** *Methods:* **This was a cross-sectional community research design study with purposive sampling. It involved 102 family caregivers of hospitalized first-ever stroke patients of two tertiary hospitals in Kelantan. The Bakas Caregiving Outcomes Score (BCOS) was used to measure life satisfaction. Multiple linear regression was used to determine the predictors of life satisfaction.** *Results:* **Out of 102 respondents, 21 were males and 81 were females with age range of 16 to 76 years. Significant predictors of life satisfaction of caregivers while caring for their hospitalized first-ever stroke family members were caregivers' health (β: -2.875, 95%CI: -5.725, -0.025, p = 0.048), patients' age (β: - 4.251, 95% CI: - 6.379, -2.123, p<0.001) and educational status of patients (β: 3.176, 95% CI: 1.083, 5.269, p = 0.003).** *Conclusion:* **This study highlighted predictors of life satisfaction among caregivers while caring for their hospitalized family members with stroke. The results may provide a basis for developing a support program for the family caregivers of hospitalized stroke patients in preparation for their continuing caregiving role at their homes.** *ASEAN Journal of Psychiatry, Vol. 15 (2): July – December 2014: 164-175.*

Keywords: Family Caregiver, First-ever Stroke Patient, Predictor Factor, Quality of Life

Introduction

Stroke is more disabling than lethal, and it is the second cause of long-term disability worldwide. The high incidence and prevalence of stroke have a major impact on family and community as it affect the quality of life (QOL) of the stroke survivors [1-5]. Almost 50% of stroke survivors have been discharged home with limitations in various body functions and emotional impairments [6-11]. Once discharged from the hospital, many stroke survivors require full or partial

assistance in their activities of daily living (ADL) [12,13].

Out of 10 to 15% of 25.7 millions of Malaysians are caregivers [14.15]. It is common in Malaysian practice that family members provide most of the assistance in activities daily living (ADL) of stroke patients during their hospitalization or at home. The caring activities done by the family members during hospitalization were physical cleanliness, oral feeding, positioning, and assisting in shower or toilet [16, 17]. These caregiving responsibilities are physically and emotionally challenging, especially for a person who has not had any prior training in carrying these roles and responsibilities [18,19].

Caring for the disabled stroke survivors during hospitalization may have severe impact on the quality of life of family caregivers [20,21,22]. Western studies have widely identified the predictors of quality of life among family caregivers and these include family caregivers' and stroke survivors' factors. However, this has not been studied much in Malaysia. The aim of this study was to determine the predictors of life satisfaction among families caregivers of hospitalized first-ever stroke patients. The results would hopefully provide an insight for health care personnels in developing a support program for family caregivers and stroke patients during hospitalization and post-discharge from the hospital [23]. Factors that have been identified to influence quality of life of family caregivers were socio-demographic characteristics and health status [22 -25]. Similarly, a Malaysian study found marital status, family income and a bedridden patients' condition to be significantly associated with caregiver quality of life [25]. However, the same study also revealed that age, ethnicity, occupation and educational level did not influence the perception of the care burden [25]. The general characteristics and physical functioning ability of the stroke survivors have been found to impact on the family caregivers' quality of life while caring for their stroke survivors [6,27,28].

Most Asian, including Malaysian families have a strong family ties. Caring for their sick family members have been a part of their roles and responsibilities. Most problems encountered by the family caregivers are not discussed openly and are generally hidden [29-31]. Family members suffered when someone in the family had a stroke [32,33]. Furthermore, it would complicate the situation if the one taking the role of caregiving is the only family member [32-35]. The purpose of the study was to determine the predictor factors of life satisfaction among family caregivers of hospitalized first-ever stroke patients in Kelantan, Malaysia. These preliminary findings of the predictor factors could be used to facilitate an effective nursing discharge plan to prepare and equip the family members as home-based caregivers.

Methods

The study was a cross-sectional community research design with purposive sampling. The family caregivers were recruited from two tertiary hospitals in Kelantan, Malaysia between January 2010 and May 2011. One hundred and two family caregivers who cared for the first-ever stroke patients in the ward. Family caregiver who met the inclusion and exclusion criteria were recruited. This study was approved by the research ethics committee at each institution, and written informed consent was obtained from all family caregivers.

Interviews were conducted in the ward prior to discharge. The information included, (i) *Socio demographic status of family caregivers and stroke survivors.* The selected predictor variables for socio demographic status were age, gender, marital status, highest level of education, working condition, household income and chronic diseases, relationship to the person with stroke [35,36,37,38], (ii) *Health status of family caregivers and stroke survivors.* The health status was measured by the Visual Analoque Scale (EQ VAS). The EQ VAS is a component of the EQ-5D measuring tool that records the family caregivers and stroke survivors self-rated health on a vertical, visual analogue where the end points are labeled "Best imaginable health state" and "Worst imaginable health state" with a range of 0 to 100 [39], (iii) *Physical functioning of stroke survivors.* The functional

independence in personal care and mobility of stroke survivors were assessed by Barthel's Index (BI) by researcher. The BI is a 10-item performance-based instrument that evaluates ADL's. Scores ranges from between 0 and 100, with a score of 100 representing the highest level of independence [40,41], (iv) *Life satisfaction of family caregivers*. The life satisfaction of the family caregivers was measured by Bakas Caregiving Outcomes Scale (BCOS). The changes in caregivers' lives since providing care for the stroke survivor prior to hospital discharge were measured by the 15 item of BCOS. BCOS is a continuous variable and were used as the criterion or dependent variable. This instrument allows both positive and negative aspects of caregiving to be scored and has satisfactory evidence of reliability and validity in family carers of stroke survivors [8,17]. Changes in social functioning, subjective well-being, and physical health are measured using a 7 point response scale. A score of 1,2 or 3 indicated a change for the worse with 1 being the worst possible change, 4 indicated no change, and scores of 5, 6 or 7 indicated an improvement with 7 being the largest possible improvement. In this study a score of 4 were indicated change for the worse. Total BCOS scores range from 15 to 105, with scores 61 and above indicating consistently positive changes and scores 60 and below indicating consistently negative changes since providing care for the stroke survivor [8,17].

Data were analyzed using Statistical Package for the Social Sciences Version 20.0 (SPSS 20.0). Descriptive statistics were used to describe the characteristic of respondents and stroke survivors and the outcomes for each items of BCOS. After simple linear regression analysis was done, a stepwise multiple linear regression was used to determine the predictor variables associated with life satisfaction of family caregivers while providing care for the stroke survivors prior hospital discharge. The results were presented with unstandardized coeficients (B) and standardized coefficients (ß) with 95% Confidence Interval (CI) and p-value with significance level set at 0.05.

Predictors of the family caregivers of the stroke survivors were selected from the previous studies and researcher's decision

[42,43,44,45,46]. The independent variables in this study were a mixture of continuous and categorical variables. The categorical variables that have more than 2 groups were coded as "dummy variables". Dummy variables is a categorical variable that uses "1" for cases that have certain category and "0" is for cases that do not have the category [37,38]. In these analyses, age of the family caregivers and stroke survivors were grouped into three level (less than 40 years old, 41-60 years old and more than 61 years old);and highest level of education (Not schooling/Primary school = 1, others = 0; Secondary school = 1, others = 0; College/University = 1, others = 0). While 2 groups of categorical variables were gender (Female = 1, Male = 0); marital status (Married = 1, Not married = 0); working condition (Working = 1, Not working = 0); chronic diseases (Yes = 1,No = 0); and relation to the person with stroke (Spouse = 1, Parent = 0); Cause of stroke (Don't know = 1, Know = 0); Choice of stroke treatment (Alternative treatment = 1, Hospital = 0). The health status of the family caregivers and stroke survivors and household income (Ringgit Malaysia/month) and debt (Ringgit Malaysia/month) and total of people living together were used as continuous variable. Meanwhile, the life satisfaction of caregiving of the family caregivers were used as continuous and criterion variables.

In the simple linear regression (SLR) analyses, all of the variables are entered one at a time to identify possible important predicted variables for the multivariables analysis (MLR). Scatter plot for each of the relationship were performed. From the results of SLR, all predictor variables with a p value of less than 0.25 were entered in the MLR with a stepwise method to determine the relationship of several independent variables to a continuous variable [38]. The checking of interaction for independent variables that significant at 0.05 were done and a new interaction variable term were created. The previous steps of MLR analysis with "enter" method were used. The multicollinearity and extreme outlier problems were identified by *the Variance Inflation Factor (<10)* and standard residual value results (± 3.3). Model assumptions are met.

Results

Of the total respondents (N = 102), majority were Malay (95.1%) with 79.4% were female compared with 20.6% men (Table 1). Mean age of the respondents were 44.50 (SD=15.42). A majority of the respondents had education up to secondary school (54.9%), 19.6% up to tertiary level, 16% up to primary school while the remaining were not schooling (9.8%). Only 38.2% were working and 61.8% were not working. About 84.3% of the family caregivers had poor health compared to 15.7% with good health. Almost half of the family caregivers had at least one chronic disease (52%) compared to none (48.0%).

Meanwhile, for the survivors, 63.7% were male compared to female (36.3%). Out of hundred and two stroke survivors, 47.1% were aged between 41 to 60 year, 40.2% were more than 61 years old and the remaining 12.7% were aged less than 40 years old with mean age were 56.52 (SD = 12.35). In terms of educational status, 32.4% had education up to secondary school, 29.4% up to primary school, 27.5%.were not schooling while the remaining 10.8% studied up to tertiary level. Fifty eight percent were working and 42.2% were not working. Most of the stroke survivors were having an ischemic stroke (91.2%) and the remaining was having hemorrhagic stroke. It is found that 95.1% of the stroke survivors perceived their health as poor compared to only 4.9% in good health.

Table 1. Socio-demographic characteristics of caregivers and stroke survivors

Characteristics	Caregiver (N=120)	Survivors (N=120)
Age [*Mean (Year) of caregiver = 44.50, SD = 15.42; Survivors 56.52, SD = 12.35*]		
Less than 20 year old	4 (3.9)	-
21-30 year old	20 (19.6)	-
31-40 year old	19 (18.6)	13 (12.7) [<40 y.o]
41-50 year old	22 (21.6)	48 (47.1) [41-60 y.o]
51-60 year old	21 (20.6)	-
>61 year old	16 (15.7)	41 (40.2)
Gender		
Female	81 (79.4)	37 (36.3)
Male	21 (20.6)	65 (63.7)
Ethnic		
Malay	97 (95.1)	95 (95.1)
Chinnese	5 (4.9)	5 (4.9)
Others	0 (0.0)	
Religions		
Muslim	99 (97.1)	99 (97.1)
Others	3 (2.9)	3 (2.9)
Marital status		
Not married	15 (14.7)	-
Married	87 (85.3)	-
Education [*Mean (years) of Caregivers =9.02, SD=4.01; Survivor = 6.50, SD=4.41*]		
Not schooling	11 (10.8)	28 (27.5)
Primary school (1-6 years)	15 (14.7)	30 (29.4)
Secondary school (7-11years)	55 (53.9)	33 (30.4)
College/University (More than 12 years)	21 (20.6)	
Working status		
Working	63 (61.8)	59 (57.8)
Not working	39 (38.2)	43 (42.2)
Presence of chronic disease		
Yes	53 (52.0)	-
No	49 (48.0)	-
Type of stroke		
Haemorraghic	-	9 (8.8)
Ischaemic	-	93 (91.2)

Physical function ability		
Problem	-	102 (100.0)
No problem	-	0 (0.0)
Stroke survivor health status [*30.08, SD=8.76*]		
Poor health	-	97 (95.1)
Good health	-	5 (4.9)

Characteristics of socio economic status of the family caregivers

Table 2 shows the characteristics of the socio economic status of the family caregivers. Sixty and seven percent of the stroke survivors were spouses and 32.4% were parent of the family caregivers. Most (72.5%) of the family caregivers had at least three people living together (including stroke survivor) and 27.5% caregivers had less than 2 people living together. Half (49.0%) of the respondents had household income of less than RM1000.00 per month, 25.5% were not having any income and 4.9% had more than RM1001 with the mean of household income being RM 618.63 (SD = 634.21). Majority (93.1%) of the respondents did not have any other financial support. About 34.3% were paying for debt every month.

Table 2. General characteristics of the socio economic status (N = 102)

Socio economic status/variables	Frequency	(%)
Relation to stroke survivor		
Spouse	69	67.6
Parent	33	32.4
Total of people living together (including stroke survivor)		
2 and less	28	27.5
More than 3	74	72.5
Household income [RM618.63, SD = 634.211] (Ringgit Malaysia/month)		
No income	26	25.5
Less than RM1000	50	49.0
More than RM1001	5	4.9
Financial support		
No	95	93.1
Yes	7	6.9
Debt (Ringgit Malaysia/month) [RM 137.75, SD = 307.55]		
Yes	35	34.3
No	67	65.7
Cause of stroke		
Don't know	91	89.2
Know	11	10.8
Choice of stroke treatment		
Alternative/Traditional	93	91.2
Hospital	9	8.8

Caregiver life satisfaction

Table 3 displays the outcome for each item of BCOS among the family caregivers of the stroke survivors. Family caregivers reported an experience of change for the worst for most of the items while caring for their stroke survivors in the hospital. The mean (SD) score were 34.95 (5.35) and minimum score were 23 and maximum score were at 46.

Table 3. The distribution of the life satisfaction (BCOS) item of the caregivers (N=102)

	Items (BCOS)	Frequency (%)	
		Change for better	Change for worst
1.	My self confidence	0 (0.0)	102 (100.0)
2.	My physical health	0 (0.0)	102 (100.0)
3.	My time for family activities	0 (0.0)	102 (100.0)
4.	My ability to cope with stress	0 (0.0)	102 (100.0)
5.	My relationship with friends	0 (0.0)	102 (100.0)
6.	My future outlook	0 (0.0)	102 (100.0)
7.	My Level of energy	0 (0.0)	102 (100.0)
8.	My emotional well-being	0 (0.0)	102 (100.0)
9.	My roles in life	0 (0.0)	102 (100.0)
10.	My time for social activities with friends	0 (0.0)	102 (100.0)
11.	My relationship with family	1 (1.0)	101(99.0)
12.	My financial well-being	0 (0.0)	102 (100.0)
13.	My Relationship with stroke survivor	5 (4.9)	95 (95.1)
14.	My physical functioning	0 (0.0)	102 (100.0)
15.	My general health	0 (0.0)	102 (100.0)
16.	My life in general	0 (0.0)	102 (100.0)

Mean (SD, Standard deviation) = 34.95 (5.35); Min = 23, Max = 46

Prediction of life satisfaction in family caregivers prior to stroke survivor hospital discharge

Table 4 describes the results of the regression analyses. Family caregiver's health was found to be a significant predictor of caregivers' life satisfaction [F (1, 100) = 11.125, p = 0.001], although the prediction was very weak (R^2 = .091). The variance contributed only 0.9% in the family caregivers' life satisfaction score. An increase of family caregiver's health score by one will increase or improve the score of the life satisfaction of family caregiver (β = 0.316, p = 0.001).

Predicting caregiving situation factors

The predictors identified for caregiving situation were stroke survivors older age and lowest level of education (primary school) as shown in Table 5. Although, the contribution of older age were very weak (R^2 = .081) in the score of family caregivers life satisfaction, an increase in stroke survivors age by one unit (β = - 3.099, p <0.004) will deteriorate or decrease the score of the family caregivers life satisfaction by 3.1. Significantly, combination of the two predictors, older age (> 61 year old) (β = -.391, p < 0.001) and lowest level of education (primary school) (β = .297, p = 0.003) of the stroke survivors added about 31.7 % (39.8 – 8.1) of the variance associated to family caregiver life satisfaction [R^2 = .398, F (2, 99) = 9.320, p < 0.001].

Table 4. Caregivers variables influencing the life satisfaction of the family caregivers (N = 102)

Variables / Caregiver factors:	Simple Linear Regression			
	B	β	95% CI	p-value
Age				
Less than 40 years old	-.865	-.079	-3.023, 1.293	0.428
41 – 60 years old	.366	.034	-1.756, 2.489	0.733
More than 61 years old	.874	.060	-2.028, 3.775	0.552
Gender				
Female	-1.081	-.082	-3.686, 1.524	0.412
Marital status				
Married	.333	.022	-2.650, 3.317	0.825
Highest level of education				
Not schooling/Primary school (0-6 years)	-1.048	-.085	-3.496, 1.401	0.398
Secondary school (7-11years)	1.553	.144	-0.559, 3.664	0.148
College/University (More than 12 tahun)	-1.233	-.090	-3.937, 1.470	0.368
Working situation				
Working	.993	.091	-1.173, 3.159	0.365
Had chronic disease	.573	.054	-1.539, 2.686	0.591
Health status	.153	.316	0.062, 0.245	0.001[a]

[a] $p < 0.01$, B = Unstandardized coefficient, β = Standardized coefficient
$R^2 = .09$ The model reasonably fits well. Model assumptions are met. There are no interaction and multicollinearity problem

Table 5. The situation of caregiving variables influencing the life satisfaction of the family caregivers prior hospital discharge (N = 102)

Variables	Simple Linear Regression			
Situation of caregiving factors: Characteristics of stroke survivors	B	β	95% CI	p-value
Age				
Less than 40 years old	1.202	.075	-1.958, 4.363	0.452
41 – 60 years old	2.454	.230	0.393, 4514	0.020[a]
More than 61 years old	-3.099	-.285	-5.165, -1.033	0.004[b]
Gender				
Male	.305	.028	-1.893, 2.502	0.784
Highest level of education				
Not schooling/Primary school (0-6 years)	1.685	.158	-0.409, 3.779	0.114
Secondary school (7-11years)	-2.242	-.201	-4.409, -0.076	0.043[a]
College/University (More than 12 tahun)	.972	.057	-2.430, 4.374	0.572
Working situation				
Working	.639	.059	-1.495, 2.776	0.554
Types of stroke				
Haemorraghic	-.434	-.023	-4.159, 3.292	0.818
Days of hospitalisation	-.222	-.090	-0.712, 0.267	0.369
Communication problem	1.734	0.070	-3.149, 6.612	0.483
Physical functioning ability	.080	.272	0.024, 0.135	0.006[c]
Health status of stroke survivors	.080	.131	-0.040, 0.201	0.188

[a] $p < 0.05$, [b] $p < 0.01$, [c] $p < 0.001$, B = Unstandardized coefficient, β = Standardized coefficient
$R^2 = .141$;   The model reasonably fits well. Model assumptions are met. There are no interaction and multicollinearity problem

Predicting environmental factors

Table 6 shows no predictor variables from the environmental factors were entered in the regression model. The environmental factors were caregiver relation with stroke survivor, total of people living together, household income, debt, financial support and caregiver knowledge: cause of stroke and choice of treatment). The correlation matrix analyses showed that all of the variables were very weak correlated to caregiver life satisfaction and not significant. The analysis failed to identify any predictors from the environmental factors that would influenced the score of the life satisfaction of the family caregivers.

Table 6. Predictor variables for environmental factors of family caregivers life satisfaction prior to hospital discharged (N = 102)

Environmental factors:	Simple Linear Regression			
	B	β	95% CI	p-value
Relation to the person with stroke				
Spouses	.510	.045	-1.747, 2.767	0.655
Household income (RM/month)	.001	.088	-0.001, 0.002	0.377
Financial support				
No	2.402	.114	-1.752, 6.555	0.254
Debt (RM/month)	.000	.020	-0.003, 0.004	0.844
Cause of stroke				
Don't know	1.372	.088	-2.025, 4.768	0.425
Choice of stroke treatment				
Alternative/traditional treatment	1.652	.088	-2.060, 5.364	0.379

B = Unstandardized coefficient, β = Standardized coefficient, CI = confidence interval
No variables were entered in the regression model.

Discussion

The majority of the family caregivers in this study were females (79.4%), and either spouses (67.6%) or children (32.4%) of the stroke survivors with mean age of 44.5 years and minimum age were 16 years old. This findings reflects the Malaysian culture, whereby females take the role of caring for their sick family members. Most of the female caregivers were either spouses or daughters of the stroke survivors. It is expected that female spouses and daughters show respect and gratitude to their husbands and parents in this manner. The caregivers satisfaction is based on their sense of being able to provide quality of care and fulfilling their caregiving responsibility [45,46]. Similarly, reported by other studies [48,49] that the majority of caregivers (64.2%; 73.3%) were women with mean age of 60.36 years and 55.9 years. It is interesting to note that the caregivers for the current study were generally younger than those in other literature. The overall score for each item of BCOS reflected that majority of the caregivers' lives changed for the worst prior hospital discharge. However, the BCOS scores did not influence the results of the predictors as much.

In this study, family caregivers' health was found to be a significant predictor of life satisfaction among them. This finding is similar to the findings of the other studies that family caregivers' general health was associated with the caregiver life satisfaction [48,49,50]. The better the caregivers health status, the better will be the caregivers' life satisfaction. Similar to the findings from the other studies, stroke survivors older age and lowest level of education were associated with negative score of family caregivers' quality of life. The different findings of this study were that a high figure (38.2%) of the family caregivers were working and were spouses, however the variables was not significantly associated with the caregivers' life satisfaction. This might be the influence of the

cultural responsibilities and religious values. In line with this, it was pointed out in earlier studies that there was a disparity in ethnic and cultural views of family support [51]. In socio-cultural stress and coping model for caregivers, it is said that the values of culture in society is reflected through social support and the way of coping. This perspective is more important than caregivers' appraisals of burden when the cultural value is highlighted as one factor to determine the overall caregiver's quality of life [52,53]. However, the miscellaneous of culture values are based on common underpinning of socio-psychology circle - stressor (i.e. caregiving stressors), appraisal (i.e the appraisal of caregiving as burdensome) and health outcome (i.e. the potential of the poor health outcome of the caregivers) [52]. Meanwhile, for the environmental factor, it is also reflected that, all of variables entered were not significant and had weak association with caregiver life satisfaction.

Implications for practice

Most stroke survivors post hospital discharge are being cared for by the family members at home. In a Malaysian family, caregivers are often among the family members, either spouses, children, siblings, or relatives. Looking after or giving care to disabled family members is given a very high priority in their life. It is suggested that social or cultural values may have some role in the development of the psycho-social ecosystem of caregivers in local population, which lead to the quality of care. Thus, the quality of care to stroke survivors leads to hidden physical and psychosocial problems of the family caregivers. For the future research, a qualitative approach could be undertaken to explore in depth the feelings and perception of the family caregivers related to caregiving.

Acknowledgements

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