The Determinants of Quality of Life in Thai Family Caregivers of Stroke Survivors

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ABSTRACT

Objective: Stroke survivors suffer from multiple health problems, leading to physical and psychological impairments or disabilities. Largely, family caregivers encounter stressful situations when providing stroke care at home, however, little is known about their quality of life (QOL) and its determinants. This study aimed to identify the determinants of QOL among Thai family caregivers of stroke survivors.

Methods: The sample consisted of stroke caregivers from two tertiary hospitals in the central region of Thailand. Data collection using a set of questionnaires was performed at the out-patient department of each hospital. Data analysis included descriptive statistics and path analysis to examine the hypothesized relationship between the study variables and QOL.

Results: A total of 300 stroke caregivers were recruited. Their age ranged from 20-84 years old, and mostly were female (76%). Determinants of QOL among family caregivers were caregivers' age, caregivers' income and care burden. Care burden was the strongest predictor which explained 64 % of the total variance ($p < .001$).

Conclusion: Sociodemographic factors impact on QOL among Thai family caregivers of stroke survivors. Caregivers' burden remains a serious issue, especially for those at an advanced age with low income who provide the care for severely dependent stroke survivors. Therefore, nurses and health care team should be aware of these determinants and develop a family intervention program to support them so as to improve their QOL.

Keywords: Family caregiver; stroke survivor; quality of life; determinants (Siriraj Med J 2019; 71: 290-296)

INTRODUCTION

Stroke is a serious global health problem. Each year, more than 6.5 million adults die from stroke and another 5 million are left permanently disabled.[1] Family caregivers provide most of the home-based care for stroke patients. Previous studies in other countries suggest that the provision of stroke care can be a significant stressor in the lives of family caregivers, negatively affecting their quality of life (QOL). The definition of QOL as proposed by the World Health Organization[2] (an individuals' perception of their physical health, psychological well-being, level of independence, and social relationships in the context of their sociocultural environment) was used to guide this study. Previous cross-national literature involving family caregivers of stroke survivors reported a negative relationship between measures of QOL and perceived caregiver burden.[3,4,5] Some but not all studies have also reported a relationship between dependency for activities

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of daily living (ADLs), age, income, social support and decreased QOL scores.[3,4,6] Cultural beliefs and values may account for some of the discrepant findings across studies.[7] Currently, little data are available regarding QOL in the context of Thai family caregivers of stroke survivors, providing little for health care providers and policymakers to develop strategies to develop family-centered support.

Similar to an American study with caregivers of stroke survivors[8], we used the Stress Process Model (SPM)[9] to frame this study. This model is composed of four domains, including background and context, stressors, mediators, and outcomes. Within a Thai context, we considered the stressor to be the degree of dependency for ADLs, potential mediators to be age, income, coping style and social support, and the measured outcome was the family caregiver's QOL score. The primary aim of this study was to examine family caregivers' QOL within a Thai context and its relationship with factors that have been previously reported to influence QOL in family caregivers from other countries who provide daily care to their family member who has survived a stroke.

MATERIALS AND METHODS

A cross-sectional study design was used to examine the variables of interest and their potential impact on family caregivers' QOL. Approval for this study was obtained from the Institution Review Board for the protection of human subjects from Mahidol University (Si 251/2558). The inclusion criteria for family caregivers were adults aged 18 years and older; self-identified as a primary caregiver that lived with the survivor and provided unpaid continuous care for a family member that had experienced a stroke at least 6 months prior to the study; and those able to speak, read, and understand Thai. The calculated sample size, using the method proposed by Hair and colleagues[10], to meet our primary objective was estimated as requiring 300 participants.

Data were collected from family caregivers at the out-patient department (OPD) of two tertiary care hospitals located in an urban area in the central region of Thailand. The first hospital is a tertiary hospital under the Ministry of Education whereas the second hospital is a tertiary hospital under the Ministry of Public Health. Both hospitals are selected because they are teaching hospitals, referral centers with certified stroke centers that could represent characteristics of stroke survivors and family caregivers throughout the country. A single interview was completed in a private area of the OPD in each hospital, either before or after the patient and family caregiver were seen in follow-up by their physician. After obtaining informed consent participants were asked questions from a sociodemographic form and asked each item from a series of standardized questionnaires. Sociodemographic data included age, marital status, and perceived income sufficiency. The Barthel Activities of Daily Living Index (BAI)[11] Thai version[12] was used to assess the ADL dependency of the stroke survivors. It is composed of 10 items, with the total score ranging from 0 to 20. Lower scores indicate high dependency. The Burden Interview (BI) developed by Zarit[7] and translated into Thai by Mapi Research Trust[13] was used to measure caregiver burden. Total BI scores range from 0 to 88, with higher scores indicative of greater perceived burden. Coping strategies used by the family caregiver were identified using the Jalowiec Coping Scale (JCS),[14] which had been previously translated into Thai.[15] The JCS is divided into three subscales: confrontive coping (constructive problem solving; 13 items), emotive coping (expressing emotions as a stress reliever; 9 items), and palliative coping (activities to make one feel better; 14 items). Total coping scores range from 36 to 180; higher scores indicative of more frequent use of that coping strategy. The Social Support Questionnaire (SSQ)[16] was translated and modified for cultural relevance[17] and was used to assess perceived social support from three potential sources: family members (5 items), relatives and friends (5 items), and healthcare providers (5 items). Total scores range from 0 to 60, with higher scores indicative of greater social support. QOL was measured by the World Health Organization Quality of Life Instrument BREF (WHOQOL-BREF) Thai version.[18] The first two items rate general health satisfaction and overall QOL, while the other 24 items gather information about physical health (7 items), psychological health (6 items), social relationships (3 items), and the environment (8 items). The total QOL scores range from 26 to 130; higher scores indicative of greater perceived QOL. Reliability was tested for each of the instruments used in the study; with Cronbach's alpha coefficients calculated for each (BAI = 0.89; BI = 0.94; JCS = 0.84; SSQ = 0.94; and WHOQOL-BREF = 0.88).

Data analysis

The data in the present study were analyzed using descriptive statistics to delineate the sociodemographic characteristics of the family caregivers and the stroke survivors. Student t-tests were used to examine for gender and age group differences in the study variables. This was followed by calculating Pearson's correlation coefficients to examine the relationships between each variable of interest and the QOL score. Finally, path analysis [using the Linear Structural Relationship (LISREL) 8.72 Program (Student version, Scientific Software International, Chicago, IL, USA)] was used to develop a best fit model. The indicators that were used to establish model fit, included: 1) the non-significant value of chi-square (χ^2); 2) the ratio of chi-square (χ^2) / degree of freedom (df) less than 2; 3) goodness of fit (GFI) greater than 0.9; 4) adjusted goodness of fit (AGFI) greater than 0.9; 5) comparative fit index (CFI) greater than 0.95; 6) root mean square error of approximation (RMSEA), and standard root mean square residual (SRMR) less than 0.05.[10] Of note, the study variables in this study were not normally distributed. Therefore, the robust maximum likelihood (RML) method using an asymptotic covariance matrix was used for input10 and the Satorra-Bentler scaled chi-square was used to indicate the value of the chi-square (χ^2) for measuring the model fit with the empirical data.

RESULTS

The ages of the participants reflected a broad range from 20 - 84 years old (M = 52.32, SD = 13.59). When examining the number of participants in each age group, the result showed that 67.7% were adults (20 - 59 years old) and 32.3% were older persons (60 years old and older). Age group differences between adults and older persons were not significant in the scores associated with coping, caregiver burden and QOL. Similar to the majority of other studies regarding caregivers, most of the participants in this study were female (76%) and married (69.7%). Two-thirds of the caregivers considered they had sufficient income and also indicated that they had secondary caregivers that helped them (mainly other family members). More than half of the participants (56%) reported physical health problems (musculoskeletal pain, stress and anxiety, and insomnia were the most frequent concerns). Table 1 summarizes the data from the standardized questionnaires. Significant gender differences were observed in the scores obtained in the measures of coping, caregiver burden and QOL. Almost half (49%) of the stroke survivors had experienced their stroke between 6 to 12 months prior to the study.

The modified model fit well with the data at $\chi^2 = 0.43$, df = 11, χ^2 /df = 0.03, p = 1.00, GFI = 0.99, AGFI = 0.98 (Fig 1). The contributions of the variables to the scores on the WHOQOL-BREF, in terms of direct, indirect, and total effects, are displayed in Table 2. Specifically, the model illustrates that the caregivers' age and income had a positive direct effect on their WHOQOL-BREF QOL scores, and the caregivers' age had a significant indirect effect on the scores through social support. Caregiver burden had a negative direct effect on the WHOQOL-BREF QOL scores and an indirect effect through coping. Social support was more powerful than coping as a mediator of WHOQOL-BREF QOL scores among the stroke caregivers. ADL dependency scores did not have a significant direct or indirect effect on the caregivers' WHOQOL-BREF QOL scores (Table 2). This best fit model explained 64% of the variance in QOL, 10% of the variance in coping, and 4% of the variance in social support.

TABLE 1. Overall and gender differences in characteristics of stroke caregivers (n = 300).

	Overall		Male (n = 72)		Female (n = 228)		P value*
Variable	**Mean**	**SD**	**Mean**	**SD**	**Mean**	**SD**	
Caregiver burden	44.65	17.59	39.81	1.84	46.18	1.12	0.007
Coping	92.60	13.74	87.84	1.17	94.10	0.87	0.001
Confrontive	42.36	7.99	28.61	0.64	32.10	0.36	
Emotive	17.22	3.98	21.62	0.51	19.69	0.43	
Palliative	33.01	5.72	39.54	0.87	40.37	0.43	
Social support	32.45	12.21	31.79	1.28	32.66	0.83	0.597
Family	11.79	6.11	12.09	0.74	11.69	0.40	
Relative	10.49	5.83	9.29	0.63	10.86	0.39	
Health care provider	10.13	4.33	10.40	0.46	10.10	0.29	
Overall QOL	75.88	14.44	79.81	1.69	74.64	0.94	0.008
Physical health	21.22	4.69	22.79	0.54	20.73	0.30	
Psychological health	18.47	3.73	19.26	0.37	18.22	0.25	
Social relationship	7.64	2.01	8.00	0.26	7.52	0.12	
Environment	22.99	4.40	23.79	0.52	22.73	0.28	

Note: * the results of the t-tests comparing male and female caregivers

TABLE 2. Direct effect, indirect effect and total effect of study variables.

Variable & impact	The modified model		
	DE	IE	TE
BETA			
Social support → QOL	.28***	-	.28***
Coping → QOL	.10*	-	.10*
GAMMA			
Age → Social support	-.18***	-	-.18***
Age → QOL	-.15***	-.05	-.20***
Income → Social support	.10	-	.10
Income → QOL	.14***	.03	.17***
ADL → Coping	.00	.00	.00
ADL → QOL	.05	-	.05
Burden → Coping	.31***	-	.31***
Burden → QOL	-.64***	.03	-.61***

Note: ***p < .001, *p < .05 **Abbreviations:** DE = Direct Effect, IE = Indirect Effect, TE = Total Effect

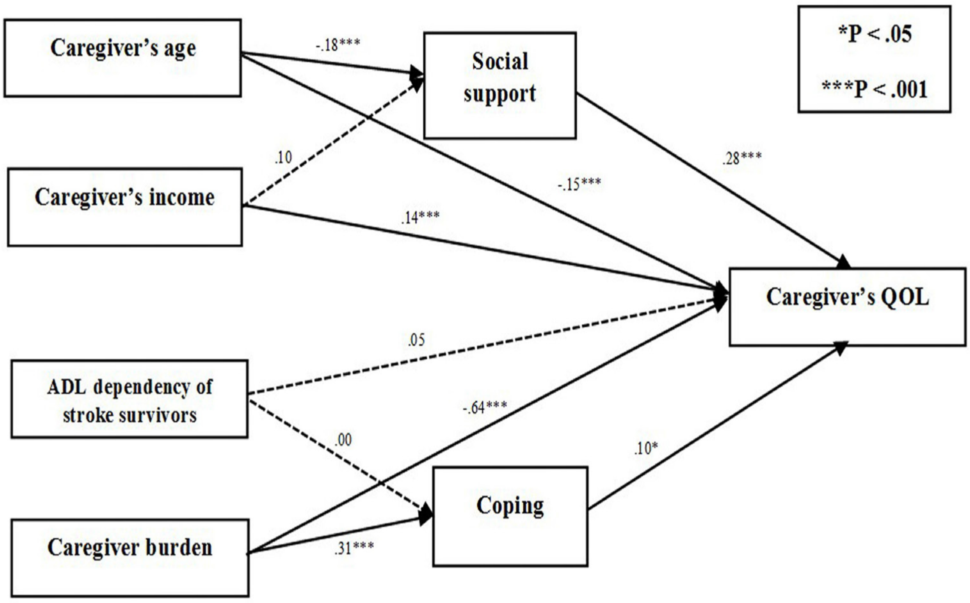

Fig 1. Determinants of quality of life in Thai family caregivers of stroke survivors.

DISCUSSION

In this study, most of the findings were congruent with the Stress Process Model (age, income, care burden). However, ADL dependency did not make a significant contribution to QOL scores. This is in contrast to some previous research[19,20] but consistent with other studies.[5,21]

Although more than 50% of caregivers reporting that they provided most of the hygiene care, mobility and emotional support, and transportation for follow-up medical, this was not related to the caregivers perceived QOL. This is consistent with a previous study that used the same theoretical model and reported that loss of functional capacity in the stroke survivor decreased leisure activities for the caregiver, however this decrease did not affect scores on the QOL measure.[8] Potential contributors to this difference include the duration of caregiving (all caregivers had been providing care for more than 6 months and 50% for more than 12 months), thus perhaps they had adapted to their caregiving role while caregiving became more structured into routines. In addition, after this time period, there may also have been improvements in ADLs that provided positive reinforcement for caregivers.[20] In addition, most of the participants (64%) had secondary caregivers to help them in providing care for their family member.

In response to the questions from the BI, some participants expressed that they were grateful to have a chance to repay their parent/spouse for past support. This sense of filial responsibility and pride in having that responsibility is consistent with Thai spiritual and cultural beliefs and values and has been noted by other Thai researchers.[22] Indeed, older adults living in care homes in Thailand feel stigmatized, reflecting a belief that others must see them as being poor with no family.[23] In the original article regarding development of the BI, Zarit and colleagues[7] cautioned that culture is important in the concept of caregiver burden. In a recent literature review, caregivers derived meaning in their caregiving from multiple sources (their personal sacrifice, a moral or religious obligation, others' expectations, social norms and a subjective choice based on love, hope, and a sense of reciprocity).[24] Thus, comparing scores obtained from cross-cultural studies must be interpreted with caution, considering interactions among individual, cultural and societal contexts. For example, BI scores reported from studies involving family caregivers of stroke survivors ranged from 29.6 to 34.9 in two Brazilian studies[5,25], 47.4 in a Turkish study[26,27], 21.6 in another Thai study[22] and 34.1 in a Japanese study.[28] In an Indian study 58% of the caregivers had BI scores over 75.[20] The mean score (44.7) observed in this study was higher than some other studies and may reflect an increased prevalence of physical health problems reported by caregivers and perhaps a more accurate estimate of caregiver burden, as suggested by other Thai researchers.[29,30] An American study calculated a cutoff score on the BI of 24 - 26 as being predicative of increased risk of depression in caregivers.[31] However, in contrast to the extensive and well-established long-term care system in North America, most Asian countries rely heavily on family members to provide care until the family member's death.[32]

As with other studies[33,34], we found financial security had a significant positive direct effect on the caregivers' QOL. This consistent finding has led to efforts to quantify the cost associated with informal care by families and to consider providing employee benefits or government subsidies to support family caregiving, especially for women who leave employment to care for parents who need care.[35,36,37] In relation to an age issue, the finding in this study revealed that about one third of the participants aged 60 years old and older. Although some previous study[38] found that the more advanced age, the more mature and experienced people have in care providing skills. However, consistent with previous stroke literature[3,4], this study revealed that advanced age had a negative direct effect on QOL. Older people tend to have health decline and therefore require support to cope with care burden for other family members who are ill. Finally, the importance of social support and adaptive coping was affirmed in our study. As reviewed in previous studies, multiple family support interventions have been developed and tested, with positive impact on QOL measures.[37,39, 40]

Limitations

This study may have limited generalizability due to a potential bias selection of participants. Based on the selection criteria, the participants were family caregivers who were able to bring their stroke relatives to follow up at the OPD. This means the ADL of their stroke relatives might have been improved. However, there may be a number of stroke survivors that have been bedridden and difficult to bring to follow up at the OPD. In these cases, the ADL dependency may make a significant contribution to the QOL scores. Therefore, further study should investigate more on those caring for stroke survivors who are bedridden at home. Qualitative studies that can yield rich text regarding factors affecting QOL of stroke caregivers would also make an important contribution to further understanding in this issue.

CONCLUSION

This study identified a number of potentially modifiable determinants (socioeconomic of caregiver, perception of care burden, and social support) that could be used to develop and test interventions to improve the QOL among family caregivers of stroke survivors in Thailand. However, our data provide evidence that such development would require consideration of gender. Qualitative studies on the lived experience of Thai male and female caregivers of stroke survivors could provide rich information about their biggest challenges, what resources would be most helpful, and what priority area(s) would improve their QOL. These data could provide further details to optimize potential the development and testing gender-sensitive and/or gender-specific interventions. The topics addressed in such an intervention could focus on improving caregivers' physical health status, providing psychological support, and creating routines that allow them for more predictability and scheduled time for social activity and for self, leading to grater QOL.

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