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COMPARING SPIRITUALITY AND QUALITY OF LIFE BETWEEN STROKE SURVIVORS AND THEIR FAMILY CAREGIVERS

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ABSTRACT

Background: Stroke results in hardship to both patients and family caregivers. The spirituality and quality of life (QOL) of stroke survivors and their caregivers may differ from each other. No study on the effect of stroke on spirituality and QOL of both stroke survivors and their caregivers is available from Malaysia. This research was performed to compare spirituality and QOL of stroke survivors and caregivers.

Materials and Methods: This was a cross-sectional study with a total of 160 stroke survivors and 160 family caregivers from Hospital Rehabilitasi Cheras and Hospital Kuala Lumpur, Malaysia. Spirituality was assessed using the Functional Assessment of Chronic Illness Therapy–Spiritual Well-Being Scale (FACIT-Sp) and QOL was assessed using the Short Form-12 Health Survey (SF-12), which has been validated in Malaysian populations. All analyses were carried out using IBM SPSS version 22. T-test was adopted to compare QOL and spirituality scores between stroke survivors and caregivers.

Result: Stroke survivors had a mean age of 53.3 ± 14.9 years and 60 % of the survivors were male. The caregiver was usually a woman (61.9%) and had a mean age of 45.2 ± 13.6 years. Caregivers rated statistically significant higher spirituality and QOL scores than stroke survivors. There were significant differences in QOL and spirituality based on gender.

Conclusion: Stroke survivors tend to have lower QOL and spirituality scores than their caregivers. This study has highlighted the need for interventions and supports not only to improve stroke survivor's health but also improve outcomes for caregiver.

Keywords: Malaysia, Quality of life, spirituality, stroke, caregivers

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1.0 Introduction

Stroke is the second leading cause of death worldwide and the leading cause of permanent disability. Globally, approximately 16.9 million people suffer from stroke each year and 5.9 million deaths (Feigin et al., 2014). These number are expected to rise to 70 million stroke survivors and 12 million stroke deaths by 2030. In Malaysia, stroke remains a major health burden and age-adjusted incidence rate of stroke was 67/100,000 in 2010 (Neelamegam et al., 2013). It was estimated an increase in age-adjusted incidence rate of ischemic stroke from 34.21 per 100,000 in 2010 to 96.21 per 100,000 in 2014 (Aziz et al., 2015). More than 60% of stroke survivors are living in the community with some level of disability, and need assistance with activities of daily living (Scherbakov, Von Haehling, Anker, Dirnagl, & Doehner, 2013). At home, stroke survivors rely on emotional and physical supports from family members, such as spouses, adult children and siblings, close friends, and sitter to aid in their recovery. Consequently, stroke affects not only stroke survivors but also their caregivers.

Spirituality refers to a sense of peace, wholeness, or harmony with a higher power, and a sense of meaning and purpose in life (Tanyi, 2002). Spirituality has been identified as a component of quality of life (QOL) that add the complexity and comprehensiveness of health outcome measures and provide more effective care strategies for those who are severely ill (WHOQoL SRPB Group, 2006). Research studies have shown the relationship between spirituality and physical and mental health among a wide range of populations including various types of cancer patients and patients with chronic illnesses. Moreover, only a few articles reported the positive effect of spirituality on QOL in stroke patients. Giaquinto, Cristiana, (2007) study of 132 stroke inpatient's spirituality and religiosity revealed that patient's religious beliefs predicted reduced anxiety and depressive symptoms (Giaquinto, Spiridigliozzi, & Caracciolo, 2007). Similarly, Johnstone et al (2008) findings showed that religious and spiritual coping associated with better mental health but not in physical health (Johnstone, Franklin, Yoon, Burris, & Shigaki, 2008). The patients' view on QOL has been reported, previous studies have showed impaired QOL of patients after stroke compared to a general population, especially physical and mental domains.

The burden of stroke affects the family caregivers and they have been found at risk for developing psychologically distress, poor QOL and health problems. Caregivers of stroke survivors have been shown to have lower QOL than norms and their quality of life may even lower than that of the care-recipients (Akosile, Okoye, Nwankwo, Akosile, & Mbada, 2011; McPherson, Wilson, Chyurlia, & Leclerc, 2011; Parag et al., 2008). In the process of caregiving, caregivers have found that spirituality helps them to cope with daily living processes and feelings of being overwhelmed with physical and emotional aspects of caring. For example, caring for persons with Alzheimer's disease, cancer, AIDS, or stroke. Caregivers also reported elevated spirituality and greater recognition of spiritual needs in caring process. Pierce et. al (2008) qualitative study explored spirituality of stroke caregivers (n = 36) revealed that they felt the presence of a greater power to improve their lives. The importance of religious practices or rituals, connectedness with nature, and interacting family

and friends were highlighted in the ways stroke caregivers cope with daily aspects of caring (Pierce, Steiner, Havens, & Tormoehlen, 2008). Although the evidence suggests the importance of spirituality and QOL in stroke survivors and caregivers, little research has been done on the comparison of spirituality and QOL in stroke survivors and caregivers.

It is important to understand and distinguish between spirituality needs of both patients and caregivers to plan and provide effective rehabilitation interventions with the aim to improving the QOL for both groups. However, the difference in spirituality and QOL, comparing stroke survivors and caregivers have never been studied. No study of the effect of stroke on spirituality and QOL of both stroke survivors and their caregivers is available from Malaysia. Thus, our research was aimed at comparing spirituality and QOL, comparing stroke survivors and caregivers.

2.0 Materials and Methods

2.1 Sample

The study used a descriptive and cross-sectional design. Participants were recruited and assessed at neurology outpatient clinic, Hospital Rehabilitasi Cheras and Hospital Kuala Lumpur, Malaysia, between December 2014 and September 2015. The inclusion criteria for the stroke survivors were: aged 18 years or older, stroke diagnosed by a neurologist, were medical stable, able to respond to study questions, and had an adult family caregiver. The exclusion criterion were: had a severe psychiatric disorder, had an acute disorder such as cancer or tumors or surgical operation in the past four weeks, and having language deficit or severe cognitive deficit due to stroke as measured by Mini Mental State Examination (MMSE < 17) (Zarina, Zahiruddin, & AH, 2007). Sampled caregivers were only those who provide structured care voluntarily and for free to the stroke survivor. Eligible caregivers included adults who met the following criteria: aged 18 years or older, living with a stroke survivor, being the partner, adult child, parent, or relative of stroke survivor, and not diagnosed with stroke.

A total of 160 stroke survivors and 160 caregivers completed the survey and participated in this study. Participants were approached for their participation while they were waiting to see a doctor. The researcher met, explained, and invited patients to participate in this study. Each stroke survivors was asked to identify an acquaintance that were considered his or her informal caregiver. Participants were requested to sign an informal consent form. Data were collected through face-to-face interview using pre-tested questionnaire. The study was approved by the Universiti Putra Malaysia Ethics Committee for Research Involving Human Subjects (JKEUPM) and the Medical Research and Ethics Committee (MREC), Ministry of Health, Malaysia.

2.2 Measures

The Short Form-12 Health Survey (SF-12) was used to assess QOL for both stroke survivors and caregivers. The SF-12 components have been shown to be a valid, reliable and responsiveness measure of QOL in stroke patients and caregivers (Pickard, Johnson, Penn, Lau, & Noseworthy, 1999). It covers both physical and mental concepts, as well as social

aspect. This 12-item instrument contains two summary scores: the physical component summary (PCS) and mental component summary (MCS) scores (Ware, Kosinski, & Keller, 1996). Both PCS and MCS scores ranges from 0 to 100, representing worst to best health. The SF-12 has been translated into Malay language and validated in postpartum mothers. The Malay version of SF-12 has been reported as having good validity and reliability with Cronbach's alpha estimates of 0.70 for MCS and 0.75 for PCS (Noor & Aziz, 2014).

Spirituality was assessed by the Functional Assessment of Chronic Illness Therapy–Spiritual Well-Being Scale (FACIT-Sp). The FACIT-Sp comprises 12 questions that assess spiritual well-being in three domains: peace, meaning, and faith. Each item is scored on a five-point Likert-type response scale: 0 = Not at all; 1 = A little bit; 2 = Somewhat; 3 = Quite a bit; and 4 = Very much). The items constituting a particular scale are averaged to generate subscale scores (ranging from 0 to 4). Higher scores reflect better spiritual well-being. The instrument has high criterion validity, predictive validity, and internal consistency (Bredle, Salsman, Debb, Arnold, & Cella, 2011).

Socio-demographic characteristics of stroke survivors and caregivers were also collected, such as age, gender, ethnicity, marital status, educational level, and employment status.

2.3 Data analyses

All analyses were conducted using IBM SPSS, version 22 and significant level was set as 0.05. Descriptive statistics were conducted to describe the characteristics of both members. Chi-square statistic was used to identify any differences between stroke caregivers and survivors on categorical variables. The independent samples t-test was used to compare the mean differences in numerical variables between caregivers and survivors. The differences between genders of both groups were tested using the one-way ANOVA. The differences between each pair of means were determined by using Post-hoc Least Significant Difference (LSD) analysis.

3.0 Result

3.1 Demographic characteristics and differences of the participants

A total of 160 stroke survivors and 160 caregivers were recruited for this study. Table 1 provides a comparison of the demographic profiles comparing stroke survivors and caregivers. The mean age of the stroke survivors was significantly higher than the caregivers ($p < 0.001$). There were significant differences between gender, with female participants more likely to be caregivers. Caregivers were also statistically significantly more likely to have completed secondary school education. Those who reported working were also significantly more likely to be caregivers. No other statistically significant differences were observed, comparing groups, within ethnicity and marital status.

3.2 Differences in spirituality and QOL

Regarding spirituality and QOL, the caregivers reported higher QOL and better spirituality (Table 2). Comparing the QOL of stroke survivors and caregivers, there was significant

difference statistically, for each of PCS and MCS ($p < 0.001$). Caregivers rated statistically significant higher meaning ($p = 0.004$) and faith scores ($p < 0.001$), indicating a greater spiritual well-being. Conversely, there were no statistically significant differences between faith scores of survivors and caregivers.

Table 1: Demographic characteristics of stroke survivors and caregivers (N = 320)

Characteristics	**Stroke Survivors (n=160)**	**Caregivers (n=160)**	**Statistics**
	n (%)	n (%)	
Age, mean (SD)	53.33 (14.88)	45.24 (13.59)	t=-5.08, p<0.001
Gender			
Male	96 (60.0)	61 (38.1)	χ^2=15.32, p<0.001
Female	64 (40.0)	99 (61.9)	
Ethnicity			
Malay	109 (68.1)	109 (68.1)	χ^2=0.18, p=0.915
Chinese	40 (25.0)	39 (24.4)	
Indian	11 (6.9)	12 (7.5)	
Educational level			
Primary	59 (36.8)	16 (10.0)	χ^2=37.80, p<0.001
Secondary	74 (46.3)	84 (52.5)	
Tertiary	27 (16.9)	60 (37.5)	
Employment status			
Work	17 (10.6)	73 (45.6)	χ^2=62.49, p<0.001
Retired	21 (13.1)	32 (20.0)	
Unemployed	122 (76.3)	55 (34.4)	
Marital Status			
Single	32 (20.0)	33 (20.6)	χ^2=2.72, p=0.437
Married	118 (73.8)	121 (75.6)	
Divorced/ Widowed	10 (6.2)	6 (3.1)	

Table 2: Spirituality and QOL scores of stroke survivors and caregivers (N = 320)

Scale	**Stroke Survivors (n=160)**	**Caregivers (n=160)**	**t**	**p**	**r**	**p**
Meaning	2.58 (0.86)	2.85 (0.86)	2.91	0.004	0.51	<0.001
Peace	2.50 (0.80)	2.65 (0.87)	1.79	0.075	0.50	<0.001
Faith	2.58 (0.85)	2.94 (0.90)	3.66	<0.001	0.46	<0.001
PCS	30.48 (16.01)	58.90 (13.99)	16.92	<0.001	0.03	0.690
MCS	43.46 (20.30)	64.04 (21.48)	8.81	<0.001	0.25	0.002

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3.3 Results based on gender

Table 3: Demographic characteristics and their relation to QOL and spirituality in stroke survivors and caregivers.

Scale	Stroke Survivors		Caregivers		F	P
	Female (n=64)	Male (n=96)	Female (n=99)	Male (n=61)		
Meaning	2.57 (0.65)	2.59 (0.87)	3.03 (0.86)	2.56 (0.79)	7.15	<0.001
Peace	2.48 (0.74)	2.51 (0.84)	2.77 (0.88)	2.50 (0.84)	2.32	0.075
Faith	2.66 (0.81)	2.53 (0.88)	3.04 (0.92)	2.77 (0.86)	5.95	0.001
PCS	26.26 (15.27)	33.30 (15.95)	59.35 (13.84)	58.23 (14.32)	100.40	<0.001
MCS	41.06 (16.79)	45.05 (22.28)	66.82 (21.00)	59.53 (21.64)	28.24	<0.001

Table 4: Post hoc LSD test for gender

Scale	Difference between groups, p-value					
	CGF vs CGM	CGF vs SSF	CGF vs SSM	CGM vs SSF	CGM vs SSM	SSF vs SSM
Meaning	<0.001	<0.001	<0.001	0.952	0.809	0.858
Faith	0.061	0.007	<0.001	0.466	0.087	0.353
PCS	0.643	<0.001	<0.001	<0.001	<0.001	0.004
MCS	0.032	<0.001	<0.001	<0.001	<0.001	0.235

CGF = Female of caregiver, CGF = Male of caregiver, SSF = Female of stroke survivor, SSM = Male of stroke survivor

The ANOVA results in Table 3 for the differences based on gender indicated that there were significant differences between males and females in terms of meaning, faith, PCS, and MCS. The Post-hoc LSD test revealed that the female caregivers had a significantly higher meaning scores than male caregivers and both genders for stroke survivors (all $p < 0.001$). The female caregivers had significantly higher faith scores than both genders for stroke survivors (female, $p = 0.007$; male, $p < 0.001$). Both male and female caregivers showed significantly higher PCS scores than stroke survivors of both genders (all $p < 0.001$). Among physical dimensions of SF-12, the mean score for PCS was significantly higher among male stroke survivors compared with female stroke survivors ($p = 0.004$). Significantly higher scores for MCS in caregivers compared with stroke survivors were shown in both genders (all $p < 0.001$). The female caregivers had a significantly higher mean of MCS compared to male caregivers ($p = 0.032$). No significant differences between caregivers and stroke survivors were observed for the peace scores.

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4.0 Discussion

To date, no other research has been reported considering simultaneously, both stroke survivors and stroke caregivers. There has been a range of stroke research on QOL, but each study is typically limited to only one samples either stroke survivors or stroke caregivers. In addition, research on spirituality among patients and caregivers, has been limited to cancer, and thus, patterns of spirituality in stroke survivors and caregivers remain largely unknown. In local stroke research such as those related to QOL, no reports of comparison between caregivers and stroke survivors were found. Thus, this is the QOL study that examined differences between stroke survivors and caregivers in Malaysia in terms of QOL and spirituality. It is important to compare QOL among caregivers and stroke survivors so as to explore caregiver burden and emotional distress that could have impact on the patient's illness and functioning.

This study examined a sample of stroke survivors and caregivers, with two key findings enhancing our understanding of variability in QOL and spirituality outcomes. First, stroke caregivers reported better QOL and spirituality than stroke survivors. Second, there was a significant differences in the QOL and spirituality between males and females of stroke survivors and caregivers. Caregivers of stroke patients face physical, emotional, social hardships and burdens. Thus, they rely on spirituality to cope with these burdens. Being a caregiver also affect the person's spirituality, such as searching for meaning, have existential questions related to their own health, uncertainty about future, and feel hope or lack hope. Greater levels of spirituality linked to reduced negative impact of caregiving stress. Caregivers with higher spirituality may perceive caregiving as part of their spiritual duties, and thus appraise the caregiving role positively. Therefore, highly spiritual caregivers may results in better mental health and physical health.

Stroke survivors' functional disabilities appear to have a greater impact on physical health. The emotional impact of stroke is as devastating as the physical effects. Stroke survivors had a significant post-stroke depression and anxiety. In addition, spiritual concern are important to stroke survivors and are significant in how they view and cope with their illness. Besides negative aspects of life, the patients identify changes in values and priorities, increased faith in God, finding meaning in life and peace of mind, all of which have been reported to result from an experience with illness and treatment.

This study found stroke survivors had lower PCS and MCS scores when compared with caregivers. This is congruent with the findings reported by Godwin and colleagues (2013) who reported that stroke survivors had lower QOL on all domains of the SF-36 as compared with those partner caregivers. Similar to those in Lund Stroke Study (Jönsson, Lindgren, Hallström, Norrving, & Lindgren, 2005), stroke survivors reported lower generic QOL than caregivers on all domains of SF-36 other than bodily pain, role emotional, and mental health at 4 months after stroke. However, stroke survivors reported QOL had significant higher in mental component summary scores of QOL when compared with caregivers during 16 months after stroke. Although the stroke patients' physical function deteriorated, their QOL improved in social, emotional, and mental domains, which might be related to their adaptation

to the disease. Social support from family and friends was also identified as an important component of adjusting life after stroke was also reported in previous study (Kruithof, van Mierlo, Visser-Meily, van Heugten, & Post, 2013) and may contribute towards better QOL. In contrast to the findings of this study, it has been noted in the literature that caregivers of stroke survivors have been shown to have lower QOL than norms and their quality of life may even lower than that of the care-recipients (Akosile et al., 2011; McPherson et al., 2011; Parag et al., 2008). The conflicting results could be due to onset time after stroke, selected QOL assessment tools, and patient and caregiver characteristics. Thus, these findings may suggest the prospective studies of QOL for stroke survivors and caregivers; and other confounders are required to examine this comparison.

This study revealed that male and female of stroke survivors and caregivers have significantly different QOL and spirituality. Male stroke survivors have significantly higher PCS scores than female stroke survivors. In agreement with previous studies, women were more likely than men to experience worsen physical aspect (Ellis, Grubaugh, & Egede, 2013) and mental aspect of QOL after stroke (Zhang, Sun, Wu, & Xia, 2013). It is plausible that women are more attentive to their feelings and reported worry more about their illness than did men. In contrast, however, Azlin and Rizal (2009) found that female stroke patients demonstrated higher QOL scores than the male in all domains except mental health. A possible explanation for this inconsistency might be explained by methodological and situational differences such as stroke patients receiving rehabilitation treatments in community centre have better physical conditions were recruited.

Female caregivers reported higher MCS and meaning when compared to male caregivers. In most cultures and countries, women are expected to care for family members. In this study, there are more females caregivers than male caregivers. Female caregivers perceive caregiving tasks as beneficial and less stressful. They may receive additional help or supports in caregiving and feel competent in providing care to family members. In contrast, male caregivers reported lower QOL. Our findings suggest that men might be carry out multiple social roles and demands, particularly caregiver, parental role together with career pressures. However, the finding in our study is in contrast to a previous study, male stroke caregivers had higher QOL in bodily pain, vitality, role emotional, and mental health domains of SF-36 than did female caregivers (Pinedo et al., 2017). Other caregiving factors such as relationship of caregiver and care-recipient (spouses, siblings, offspring, and parents), caregiving stress, and caregiving esteem, may influence their caregiving experiences and their QOL.

The current study has a number of methodological limitations that should be noted. First, the cross-sectional study design limits conclusions regarding the direction of relationship between gender, spirituality, and QOL. Second, all variables were self-reported and may not reflect objective health status. Future studies should include behavioral and psychological indicators of depression and QOL. Third, the small sample size and only one study location could limit the generalization of study findings to stroke patients and caregivers or to Malaysian populations. Finally, the present study did not examine other important determinants of stroke experience, such as characteristics of patients and caregivers, caregiving burden and appraisals, and social supports that may affect the QOL and spirituality.

5.0 Conclusion and recommendation

The disability of stroke affects both stroke survivors and caregivers. Stroke survivors tend to have lower QOL and spirituality scores than their caregivers. Despite these limitations, the findings add important information related to the differences in QOL and spirituality of stroke patients and their family caregivers and to clarity the effects of gender on QOL and spirituality of stroke survivors and their caregivers. Family caregivers play an important role in the stroke recovery process, and hence, it is useful to find strategies to improve the caregiver's QOL. This study also has highlighted the need for interventions and supports not only to improve caregiver health, but also enhance outcomes for stroke survivors.

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Declaration

Authors declare no conflict of interest.

Authors contribution

Author 1: study conception and design, data collection and analysis, manuscript writing
Author 2: study conception and design, supervising the research, final review of the manuscript
Author 3 & 4: supervising the research and review of manuscript

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