Quality of Life and its associated factors among caregivers of patients with dementia – A cross-sectional study in Kuching, Sarawak, Malaysia

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Abstract

Background: This study aimed to determine the quality of life and its associated factors among caregivers of patients with dementia in Kuching, Sarawak, Malaysia. *Methods*: This cross-sectional study was carried out among caregivers for dementia patients who visited three main hospitals in Kuching, Sarawak. Using a validated questionnaire, data was obtained based on socio-demographic profile, patient and caregiving characteristics, supports needs by caregivers, and quality of life (QoL) of caregivers modified from Zarit Burden Interview (ZBI), Hospital Anxiety and Depression Scale (HADS) and Evaluation's Scale of the Caregiver's QoL. *Results*: A total of 217 caregivers participated with response rate of 99.6%, with 67.3% female and 63.1% Chinese. Most respondent provide care for their parents (62.7%), and stay with patients (67.3%). Average duration of care was 4.2 years (SD±3.72). Resource referral (M=3.52, SD±1.334) and education support (M=3.67, SD±1.054) was highest need. Majority respondents experienced little to no burden (59%). Most respondents were not depressed (98.1%). The QoL of respondents was satisfactory (M=41.36, SD±25.840). Gender of caregivers, patients with behavioural and psychological symptoms of dementia, duration of caregiving, respite care need, caregiver disability or illness, belonging support need, education support need were significantly associated with QoL of caregivers (p<0.05).
Conclusion: This study on QoL of caregivers of dementia patients in Sarawak, Malaysia shows that it can be influenced by many factors, both at the caregivers' level as well as the patients themselves. Therefore, intervention should aim at patients and their caregivers, and within community and healthcare settings.

Keywords: quality of life, dementia, caregiving, support needs, Sarawak, Malaysia

INTRODUCTION

Dementia is a collective symptom or a syndrome of neurodegenerative diseases, in which there is a deterioration in cognitive function.[1] It is usually chronic and progressive in nature, and often disrupts a person's Activity of Daily Livings (ADLs).[1] There are many causes of dementia - infective and reversible type or non-infective and irreversible in nature.[2] The risk of getting dementia is still under rigorous study, but experts generally advised to counter risk of vascular disease such as in many other Non-Communicable Diseases (NCDs).[3] The clinical presentation of dementia may differ depending on its type especially in the early stage. However, memory loss and increasing dependency on caregivers are almost exclusive features at later stage.[1] According to Ministry of Health Malaysia[4], 15% of people with

dementia have a potentially treatable cause, but the prevalence of reversible dementia is only 1%. Therefore, the non-infective cause of dementia is a more concerned issue as it is the major cause of increasing in Disability-Adjusted Life-Years (DALYs) and contributes to the burden in medical care or even the society.[5]

Like in many other countries, Malaysia has deinstitutionalized its mental health care since the 1970s, focusing on community based healthcare.[6] Apart from empowering the people with the knowledge regarding the diseases, patients were slowly reintroduced into the society provided they were stable enough. The care of patient then falls partly into the hand of the informal caregivers who are closest to the patients. However, these caregivers may not be ready or well-trained to cope with the task as professional health care providers.

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Family caregiving can be both rewarding and stressful to caregivers. However, more negative aspects of caregiving were reported including increased physical ailments (headaches and backaches), mental health consequences (stress or distress, depression, emotional), burden, cognitive problems, inadequate sleep and self-care, and financial burden when comparing a caregiver to a non-caregiver.[7] This in return affects the quality of life of caregivers.

Study by Miranda-Castillo *et al.*[8] reported 35.4% of caregivers were found to be depressed whilst 66.7% of them had scored high level of burden in caregiving. Being female, spousal caregivers, caregivers who cohabit with patient, caregivers of lower income or financial inadequacy group exerts greater strain and psychological morbidity to the caregivers.[9] Sarkar[10] in his study found that caregiving duration was significantly related to depression of caregivers. Increasing frequencies of care, later stages of dementia were found to contribute to the poorer health-related quality of life (QoL) of a caregiver.[11]

There are many ways to help caregivers of dementia patients in coping with their stress and burden, support is one of it. Support helps to provide a buffer against stress and burden by increasing the perception that resources are available to help to relieve stress.[12] Past studies have supported a connection between social support and mental health outcomes in various populations where higher levels of social support have improved the quality of life of both patients and their caregivers. Many conceptualized models on social support have been developed but at the broadest level, these models focused on structural (i.e. social networks) or functional (i.e. tangible aid or emotional support) component of support.[13-15]

There were few Malaysian studies on the wellbeing of caregivers of dementia patients but mostly focused on the burden of care, not on the quality of life as a whole.[16-18] One study carried out in Sarawak used SF36 in measuring QoL of the caregivers of dementia.[19] Our study used the validated caregiver's questionnaire specially for caregivers of patients with dementia, adopted from Pixel studies[20] which dealt with difficulties faced by informal caregivers of dementia patients cared for at home. This instrument would help in determining the impact of care on caregivers of patients with dementia by investigating the quality of life and its associated factors.

METHODS

This cross-sectional study was carried out in Kuching, the capital city of Sarawak, with a population of 607,000. The selected study areas were the state's only tertiary hospital Hospital Umum Sarawak (Sarawak General Hospital, SGH), the Cardiac Center of SGH (also known as Pusat Jantung Hospital Umum Sarawak, PJHUS) and Hospital Sentosa (the state's only Mental Hospital) that run memory clinic for dementia patients. The sampled population of this study were the caregivers for dementia patients who visited the memory clinics at the above mentioned hospitals.

The respondents included in the study were Malaysian who are 18 years of age and above, has been caregivers for dementia patient diagnosed by Psychiatrist, Physician (including Geriatrician and Family Medicine Specialist), and has been caregiving at least 6 months.

This study employed universal sampling (take all) as sampling method in view of precious samples (limited number of patients) and face to face interview was carried for data collection.

The researcher approached patients' caregiver at the clinic day, state the intention of study and obtained their oral and written consent for the study. Caregivers were interviewed face to face at a distance from the patient as there was no separate empty room, and this also allows the caregivers to monitor the patients during the interview sessions.

The questionnaire consists of four sections: (1) Socio-demographic profile; (2) Patient characteristics and caregiving characteristics; (3) Supports needed by caregivers using Interpersonal Support Evaluation List-12 (ISEL-12) which consists 12 items short-form.[14] The instrument provides overall measure of perceived social support at three subscales (appraisal, belonging and tangible support). The scoring system was further modified to adjust to the need of this study from 4-point Likert's scale ("definitely false, probably false, probably true, definitely true") to 5-point Likert's scale (strongly disagree, disagree, neither disagree or agree, agree, strongly agree"). To compute scoring for each sub-scales, item 1, 2, 7, 8, 11 and 12 were reversed coded. Each of the subscale was generated based on: Appraisal support (item 2, 4, 6 and 11); Belonging support (item 1, 5, 7 and 9); and Tangible support (item 3, 8, 10 and 12). Two additional questions were added to assess resource referral support ("you know where to find information regarding patient's condition") and educational support ("the education in patient care given to you is adequate"). All scores were kept continuous. In

this section, the lower the score obtained means the lesser support the caregivers received and thus the higher the needs were. (4) Quality of Life (QoL) of caregivers was modified and combined from three tools – Zarit Burden Interview (ZBI)[21], Hospital Anxiety and Depression Scale (HADS)[22], and Evaluation's Scale of the Caregiver's QoL[23] to create five domains of QoL: Behavioral competence to face difficulties created by the disease, QoL in relation to the environment, Psychological perception of the situation, Possible perception of distress, and Caregiving burden. ZBI is an instrument with 22 items scale developed for caregivers for patient with dementia. It was assessed using 5 point Likert scale, with 0=never, 1=rarely, 2=sometimes, 3=quiet frequently, and 4=nearly always. Minimum score is 0 while maximum score is 88. HADS is a 14 items screening tool developed to detect depression (7 items) and anxiety (7 items). For this study, only the depression subscale of 7 items was adopted. This instrument uses 0-3 point's Likert scale. The minimum score is 0 and maximum is 21. Higher score indicating the probability of caregiver has depression. Evaluation's Scale of the Caregiver's QoL is a tool that enabled the researcher to observe caregivers' behavioural capacities to face difficulties generated by patient (item 44, 50 and 58), relation with the environment (item 45, 47, 48, 54, 57 and 59), psychological perception of the situation (item 46, 53 and 60) and perception of a possible stress (item 49, 51, 52, 55, 56 and 61). However, 2 items "do you feel depressed?" was replaced with HADS and "do you feel burdened" was replaced with ZBI. These two items may not able to measure depression and burden explicitly, therefore a more detailed assessment on caregiving burden and depression using ZBI and depression component of HADs was chosen. By combining all, the original Evaluation's Scale of the Caregiver's QoL instrument of 18 items has been combined with HADS and ZBI and total up to 47 items (Appendix 1). Minimum score is 0 while maximum score is 199. Higher score indicating poorer quality of life.

Thirty caregivers were invited from the psychiatric clinics from three centres to participate in the pilot study of the questionnaires. The Cronbach's alpha for individual tools under section 4 was reported ranging from 0.724 to 0.825, met the acceptable reliability. Thus, no item was removed from the questionnaire.

Data entry and analysis were performed using SPSS version 22.0. Data was checked and cleaned for outliers. Forward, Backward and Enter methods in multiple linear regression were used to obtain a final equation model. P value of <0.05 was considered to be statistically significant. The power analysis of multiple linear regression was calculated using Cohen's f $2= R2/(1-R2)$, where f $2=0.02$ is small effect size, f $2 = 0.15$ is medium effect size and f $2 =0.35$ is large effect size.

Ethical approval was sought from the Ethics Committee of Faculty of Medicine and Health Sciences (FMHS) of UNIMAS; registration with National Medical Research Register (NMRR no.: NMRR-15-1477-26579), MOH; approval from SGH, Cardiac Centre of SGH and Sentosa Hospital directors; verbal and written informed consent from respondents.

RESULTS

A total of 225 participants were invited from the three centres, 217 were included into the study. Eight respondents refused to participate in the study. The response rate was 99.6%. Table 1 and 2 show the socio-demographic profile of the respondents and the characteristics of care they provide for the dementia patients. As shown, the mean age of the patients was more than two thirds of the patients was 77 years, about a third each was mild, moderate and severe. The behavioural and psychological symptoms of dementia (BPSD) was found in more than half of the patients. More than two thirds of the caregivers were female, two thirds were ethnic Chinese. The mean scores of support needs and QoL are shown in Table 3. There was support needs in all five areas, with belonging support with highest score, followed by tangible and appraisal needs.

All the significant independent factors extracted from the binary analysis were then analysed using Multiple Linear regression. The results of the significant variables are presented in Table 4, together with the unstandardized beta coefficient and 95% confidence interval. As shown, the caregiver's gender, patient's BPSD status, duration of caregiving, respite care need by caregivers, caregivers with no illness or disability, belonging support and education support were significantly associated with QoL of caregivers (p<0.05).

DISCUSSION

The current study involved a total of 225 caregivers for dementia patients, with the response rate of 99.6%. This study showed that more than two thirds of the caregivers were female, consistent with the studies by Jennings et al.[24] and Santos et al.[25] This is not unusual as Malaysia

Table 1: Socio-demographic characteristics of the respondents and dementia patients (N=217)

	n (%)	Mean (SD)
Respondent		
Gender		
Male	71 (32.7)	
Female	146 (67.3)	
Age (year)		52.3 (14.76)
Ethnicity		
Chinese	137 (63.1)	
Bidayuh	36 (12.0)	
Malay	32 (14.7)	
Iban	21 (9.7)	
Others	1 (0.5)	
Employment status		
Full-time working	109 (50.2)	
Part-time/no working	108 (49.8)	
Education level		
None	10 (4.6)	
Primary school	23 (10.6)	
Secondary school	114 (52.5)	
Tertiary	70 (32.3)	
Monthly household Income (MYR) (n=210)		
<2300	102 (48.6)	
2300-5599	63 (30.0)	
≥5600	45 (21.4)	
Dementia patient		
Gender		
Male	88 (40.6)	
Female	129 (59.4)	
Age (year)		77.3 (10.16)
BPSD	114 (52.5)	
Severity of dementia		
Mild	89 (41.0)	
Moderate	67 (30.9)	
Severe	61 (28.1)	

BPSD=Behavioural and Psychological symptoms of Dementia

Table 2: Characteristics of care for dementia patients (N=217)

	n(%)	Mean (SD)
Patient-caregiver relationship		
Father	44 (20.3)	
Mother	92 (42.4)	
Siblings	7 (3.2)	
Spouse	49 (22.6)	
Others	25 (11.5)	
Duration of caregiving (year)		4.2 (3.72)
Residence with patient	146 (67.3)	
Respite care need	111 (51.2)	
Caregiver disability or illness	76 (35.0)	

Table 3: Descriptive information on QoL and Support needs (N=217)

	n (%)	Mean(SD)	min	max
Support needs				
Resource referral		3.52 (1.334)	1	5
Education		3.67 (1.054)	1	5
Appraisal		3.76 (0.663)	2	5
Tangible		3.83 (0.717)	2	5
Belonging		3.87 (0.860)	1	5
Quality of Life		41.36 (25.84)	0	131
Satisfactory[1] (≥41.36)	130 (59.9%)			
Unsatisfactory (<41.36)	87 (40.1%)			
Behavioral competence to face difficulties created by the disease		3.76(3.946)	0	15
QoL in relation to the environment		4.91(6.104)	0	25
Psychological perception of the situation		4.19 (4.632)	0	15
Possible perception of distress (HADs depression component)		8.70 (7.683)	0	37
Normal (0-7)	213 (98.1%)			
Mild (8-10)	3 (1.4%)			
Moderate (11-14)	1 (0.5%)			
Severe (15-21)	0 (0.0%)			
Caregiving burden (ZBI)		19.80(12.274)	0	66
Little or no (0-20)	128 (59.0%)			
Mild to moderate (21-40)	76 (35.0%)			
Moderate to severe (40-60)	11 (5.1%)			
Severe (61-88)	2 (0.9%)			

[1]Using mean score of 41.36 as cut-off point

Table 4: Multiple Linear Regression analysis for association between quality of life, support needs, socio-demographic characteristics of respondents and dementia patients, and characteristics of care for dementia patients (N=217)

	Adj b	95% CI	t-statistics	P value
Caregiver gender (Male=ref)	7.429	1.553, 13.305	2.492	0.013
BPSD (no=ref)	-5.949	-11.674, -0.223	-2.048	0.042
Duration of caregiving (year)	0.957	0.204, 1.711	2.506	0.013
Respite care need (no=ref)	-14.612	-20.223, -9.002	-5.135	<.0001
Caregiver disability or illness (no=ref)	-8.275	-14.101, -2.449	-2.800	0.006
Belonging Support needs	-7.445	-11.243, -3.647	-3.865	<.0001
Education Support Needs	-4.305	-7.033, -1.576	-3.110	0.002

Adjusted for gender; $Adj.R^2$=0.434; The model fits reasonably well. Model assumptions were met. There was no interaction between independent variables and multi-collinearity problem.

is an Asian country where the women are often shouldered with the task of taking care the young and the elderly ones while the men do the earning to support the family. The results also showed that two thirds of the caregivers were Chinese, probably because two of the hospitals (Sarawak General Hospital and Sentosa Hospital) are located in the urban areas where majority of the Chinese are residing. A large proportion of the caregivers were children of the patients (62.9%), unlike in other countries where higher proportion of the caregivers of spousal.[24,25] This was probably due to the norm in Asian family where most of them live in an extended family that consist of parents, children and grandchildren.

About 60% of the patients in this study were female, consistent with most of the United State and European reports.[26] One of the reasons given was females have greater longevity and risk of developing dementia increases with age.[27] The behavioural and psychological symptoms of dementia was found in more than half of the patients, coincide with the more severity of dementia (moderate and severe degree=59%). As explained by Reisberg *et al*.[28], behavioural changes tend to occur at later stage of dementia in tandem with the severity of the disease.

The results on support needs indicated all the five support needs; belonging support need was rated with the highest score. When translated it meant they experienced better sense of belongingness, that the communities including their own families have not forgotten them and recognized their sacrifices in caregiving. On the other hand, resource referral need was rated the lowest, indicating the caregivers need more support in obtaining information referrals to help them in caregiving and to cope with patient care. Study by Abramsohn *et al*.[29] found that main barrier to resource referral was the inability of the caregivers to leave the patients with dementia unattended and lack of interest in participating any social events.

The multiple linear regression analysis findings showed that caregiver's gender, patient's BPSD status, duration of caregiving, respite care need by caregivers, caregivers with no illness or disability, belonging support and education support were significantly associated with QoL of caregivers (p<0.05). Male caregivers generally had better QoL compared to their female counterpart, consistent with other studies.[20,30] Many past studies reported female caregivers have been known to be highly susceptible to depression and distress, therefore they experience greater mental and physical strain in providing care, which explained their quality of life are worse than men.[31]

Patients with BSPD demands more attention compared to those without BPSD. They may have difficulty in expressing themselves and communicating that can escalate to unintentional verbal and physical abuse to the caregiver. Poulshock and Deimling[32] in their model of caregiver strain have explained that dementia causes dependency and behaviour problem in patient which subsequently lead to burden and strain to caregiver.

Living with dementia patients also require long hours of care, as such that the caregivers have limited time for themselves, and lesser time with their own social life. The caregivers need adequate belonging support in order to feel that the community is still there for him/her, particularly the support from family members and friends. Dementia caregivers were reported to have increased risk of health problems including cardiovascular diseases, low immunity, low physical activity, sleep disorders compared to non-caregivers.[33,34] Increase of physical morbidity affect the quality of life of caregivers, supported by the findings of this study where caregivers with illness or disability were found to have lower quality of life compared to those who without illness. Sorensen & Conwell[35] suggested that to improve quality of life of caregiver, sufficient rest from respite care is important. This temporary away from caring for dementia patients will help the caregiver to regain their mental capacity and balance in life after the exhaustion of caregiving.[36]

Support in the form of education (information and knowledge from health professionals and support group) provides a buffer against burden and stress faced by caregivers.[12] A good support programme provides education and information to caregivers on how to cope with anxiety, depression and other health issues, as well the understanding and course of the disease, along with training in caregiving will ease the burden of the dementia caregivers. In Malaysia, support group such as National Dementia Caregivers support network is available to provide secure and welcoming environment for caregivers' sharing, foster interaction among caregivers on practical tips and coping strategies and conduct of forum and talks to educate caregivers. Nevertheless, such establishment is only available in certain localities but not Sarawak.

Several limitations are acknowledged in this study. First, the data collection of this study was based on questionnaire, therefore response

bias was unavoidable. Second, the recruitment of the respondents was based on bigger health setting – hospitals. Other dementia patients who seek treatment at the community clinics were not included in this study. Therefore, generalization of this research findings is limited to the caregivers of similar background.

The issue of QoL of caregivers for dementia patients is very complex and influenced by many factors. Interventions should aim at simultaneous management of both patient and caregiver. It is crucial to design a strategic care plan that could maintain the QoL of caregivers and their functionality. It requires commitment and collaboration of multiple agencies including governmental, non-governmental and the society as a whole, in meeting the needs of caregivers.

DISCLOSURE

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