Association between Caregiver Burden with Feeding Problems and Functional Status of Patients with Dementia

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ABSTRACT

Introduction: Feeding difficulty and functional disability are common problems among patients with dementia but their influence on caregivers' burden has not been addressed comprehensively. Thus, this study aimed to determine the association between feeding problems, functional status and caregiver burden among patients with dementia who receive outpatient treatment at Universiti Kebangsaan Malaysia Medical Centre (UKMMC) in Kuala Lumpur, Malaysia, as compared to their non-demented counterparts. Methods: A cross-sectional comparative study was conducted among 30 patients with dementia (12 men, 18 women, mean age 75 ± 7 years old) and 60 subjects without dementia (25 men, 35 women, mean age 69 ± 7 years), as well as their caregivers. Subjects' functional status, feeding problems and also caregiver burden were assessed using Activities of Daily Livings (ADLs) and Instrumental Activities of Daily Living (IADL) questionnaire, The Edinburgh Feeding Evaluation in Dementia Questionnaire (EdFED-Q) and Zarit Burden Interview (ZBI), respectively. Subjects were also measured for height and weight. Results: Patients with dementia needed supervision (50%) and physical help during mealtime (40%). The mean functional status score of these patients was higher than the patients without dementia (p<0.05). Caregiver burden score was positively correlated with the EdFED-Q score (r=0.405, p<0.05) but negatively correlated with functional status score (r=-0.475, p<0.01). Further, multiple regression analysis showed that after adjustment for age, EdFED-Q score and functional status remained correlated with caregiver burden at R² of 0.210. **Conclusion:** Caregiver burden is associated with feeding problems and functional disability among patients with dementia. There is a need to educate the caregivers in order to improve the quality of life of both carers and the demented patients.

Key words: Caregiver burden, dementia, feeding problems, functional status, outpatient

INTRODUCTION

Dementia is an incurable, troubling disease of the elderly and it is expected to be the most important health problem as the population ages (Azlina Wati, Hawthorne & Hassan, 2011). According to an international report in 2009 (Alzheimer's

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Disease International, 2009), the prevalence of dementia will double for each increase of 5 years after age 65. Meanwhile, it was reported in Malaysia that the prevalence rate of dementia is 14.3% (Tengku Aizan *et al.*, 2010).

Elderly individuals suffering from dementia and living under long-term care usually require assistance and supervision during feeding (Chang, 2012) due to their cognitive deterioration. A study in Taiwan indicated the loss of motor control and concentration during feeding leading to a number of feeding problems (Chang & Roberts, 2008a). Functional status has a drastic impact on life expectancy of a person. Individuals with disabilities in carrying out their activities of daily living (ADL) will have a shorter life span, usually leading to a disabled state at the end of their life (Keeler et al., 2010). It is believed that patients with dementia have a poorer functional and nutritional status compared with patients without the condition (Zekry et al., 2008). In fact, functional performance of patients with dementia is significantly associated with the severity of dementia (Shiau et al., 2006).

Caring for someone with dementia is totally engrossing; it is known that people are usually forced to take care of the person (Andren & Elmstahl, 2008). Almost all of the caregivers of patients with dementia (90%) experience a certain degree of burden (Karlikaya et al., 2005) and experience a high level of depression (Braun et al., 2010; Schulz et al., 2008). A local study on dementia found perceived burden among caregivers to be associated with care-recipient factors (severity of illness) rather than caregiver factors (gender, duration of caregiving or kinship) (Rosdinom et al., 2011). Little is known about the association between feeding problems and functional status on caregiver burden. Thus, this study aimed to determine the association between feeding problems and functional status on caregiver burden among patients with dementia and their caregivers, and compare this finding

with the magnitude among patients without dementia and their caregivers.

METHODS

Study design

A cross-sectional comparative study among 30 outpatients with dementia and 60 outpatients without dementia at Universiti Kebangsaan Malaysia Medical Centre (UKMMC) and their caregivers was conducted in April to June 2012. Ethical approval was obtained from the Medical Research Ethics Committee of Universiti Kebangsaan Malaysia (UKM). Informed consent was obtained from the subjects and their caregivers.

Sampling and subjects

Subjects were selected through convenience sampling from the outpatient registration list of the psychiatric and medical clinics of UKMMC. Inclusion criteria for patients with dementia were aged 60 years or more, being diagnosed with dementia by psychogeriatricians, receiving outpatient treatment at UKMMC, were on oral feeding, had caregivers that were able to communicate (not deaf or mute) and did not have any terminal or uncontrolled chronic diseases. Inclusion criteria for patients without dementia were aged 60 years and above, receiving outpatient treatment at UKMMC, had caregivers that were able to communicate (not deaf or mute), were on oral feeding, did not have dementia and mental health problems and any terminal or uncontrolled chronic diseases. Exclusion criteria for both groups (with and without dementia) were subjects without caregivers, on enteral feeding and with terminal or uncontrolled chronic diseases. Subjects without dementia with a Mini-Mental State Examination (MMSE) score of less than 24 were also excluded. Inclusion criteria for caregivers were at least 18 years old, had been involved in the care of the patients for at least six months, providing at least four hours of supervision or direct assistance per day to the patients and were able to communicate (not deaf or mute). Exclusion criteria for caregivers were those having mental health problems and not being able to communicate (deaf or mute). Both groups of subjects were matched for gender and ethnicity.

Sample size was calculated using the formula of unequal size groups, with the second group double in size in order to increase the power of the study due to the limitation in getting a large sample for the first group, as exemplified by patients with dementia (Whitley & Ball 2002).

Data collection

Caregivers of subjects were interviewed to obtain information on socio-demographis and health profile of the patients and caregivers themselves at the outpatient clinics of UKMMC. A household visit was also carried out to collect data among patients with dementia who were not able to come to the outpatient clinics. The interview was conducted by dietetic students who had been subjected to training sessions prior to data collection. Prior to the recruitment, the Mini-Mental State Examination (MMSE) (Folstein, Folstein & McHugh, 1975) test was used to assess the cognitive function of patients without dementia to ensure that they had good cognitive function. Feeding problems were measured using Edinburgh Feeding Evaluation in Dementia Questionnaire (EdFED-Q) (Watson, 1993) and caregivers' burden was assessed using Zarit Burden Interview (ZBI) (Zarit, Reever & Bach-Peterson, 1980). Functional status was evaluated using Katz Index of Independence in Activities of Daily Living (ADLs) (Katz et al., 1963) and Instrumental Activities of Daily Living Scale (IADLs) (Lawton & Brody, 1969). Functional status score was obtained by summing up the scores of ADLs and IADLs. All questionnaires were back-to-back translated from English to Malay prior to the study.

Anthropometric measurements including weight and height were taken using standard techniques. Height was measured using Seca Bodymeter Model 201 (SECA, Germany) to the nearest 0.1cm and weight was measured using Tanita HD 309 Digital Weighing Scale (Tanita, Japan) to the nearest 0.1kg. Height for patients who were unable to stand straight was derived from an equation for its prediction from arm span and demi spans or knee height (Suzana & Ng, 2003). Weight for patients who were wheelchair-bound was derived from an equation for its prediction from mid-upper arm circumference (MUAC) and calf circumference (CC) (Chumlea et al., 1988). Body Mass Index (BMI) of each subject was calculated using the following formula: weight (kg)/height (m²) and classified based on the cut-off points in the Nutrition Screening Initiative (1991).

Statistical analysis

Statistical analysis was carried out using Statistical Package for Social Sciences (SPSS) version 16.0. Data normality was assessed using Shapiro-Wilk test. Descriptive statistics in the form of frequencies and mean \pm standard deviation are reported. In this study, parametric variables were analysed using independent *t*-test and Pearson correlation. Meanwhile, Mann-Whitney U test, Spearman correlation and Chi-square test were used for non-parametric data analyses. Statistical significance was pre-set at *p*<0.05.

RESULTS

Socio-demographic and health profiles of subjects

A total of 30 patients with dementia and 60 patients without dementia participated in this study. Most of the subjects were Chinese, married and lived with their spouse or children, as shown in Table 1. Most of the subjects suffered from hypertension (64.4%),

visual impairment (53.3%) and diabetes mellitus (45.6%). Fall (38.9%) was the most common geriatric event reported by the subjects. The mean age of subjects with dementia (75 \pm 7 years) was higher than the subjects without dementia (69 \pm 7 years) (p<0.01). A higher percentage of subjects with dementia received no formal education (23.3%) compared to those without dementia (5.0%) (p<0.05). Subjects with dementia were also more likely to have dental problems, incontinence and immobility (p<0.05).

Anthropometric and functional profiles

Table 2 shows that patients without dementia were heavier and had a higher BMI than those with dementia (p<0.01 for both parameters). A total of 50% of the subjects with dementia were underweight as compared to 25% among subjects without dementia. The score of functional status for subjects with dementia was lower compared to subjects without dementia (p<0.05) (Table 2). The most frequent functional disabilities among subjects with dementia were bathing (73.3%), dressing (56.7%) and toileting (50%). Difficulties in purchasing grocery (90%) and transportation (86.7%) were the two most common IADL limitations faced by subjects with dementia.

Nutrient intake

As shown in Table 3, there were no significant differences in energy and nutrient intakes of both subjects with dementia and no dementia. Intakes of all nutrients were below the Malaysian Recommended Nutrient Intake, with the exception of iron.

Feeding problems

Table 4 indicates that the most common feeding problems in subjects with dementia were the requirement of close supervision during feeding (60.0%), food spillage (53.3%) and physical assistance during the meal (50.0%). Food refusal most often occurred in

patients with no dementia (20.0%); however, this problem was also frequently found in care-recipients with dementia (36.6%). The score of EdFED-Q for subjects with dementia was higher than those without dementia (p<0.05) (Table 5).

Socio-demographics of caregivers

As shown in Table 5, most of the caregivers were women, married, received formal education, working, had their own salary and were children of the patients. Caregiving duration for subjects with dementia was significantly longer than those without dementia (p<0.01).

Caregiver burden level

Caregivers of subjects with dementia had a higher score of caregiver burden (32.93 +21.11) compared with caregivers of subjects without dementia (11.10+9.61) (p<0.05). In addition, the burden scale for caregivers of subjects with dementia (2.03+1.03) was also found to be larger than the scale of burden of looking after subjects without dementia (1.13+0.34) (p<0.05) (Table 5). Thus, a higher percentage of caregivers of subjects with dementia had a moderate (23.3%) and severe level of burden (10%).

Association between caregiver burden with feeding problems and functional status

Univariate analysis indicated that among the variables investigated, that is, duration of diagnosis, economic status, duration of care, age, EdFED and functional status, only EdFED (r=0.405, p<0.05) and functional status (r=-0.475, p<0.01) correlated with caregiver burden score (Table 6). Further, multiple regression analysis showed that after adjustment for age, EdFED and functional status remained correlated with caregiver burden at R^2 of 0.210.

Table 1. Socio-demographic and health profiles of subjects [Presented as n (%)]

Characteristics	Subjects with dementia			Subjects without dementia		Total	
	(n	=30)		(n=60)	(n	=90)	
Gender							
Men	12	40.0	25	41.7	37	41.1	
Women	18	60.0	35	58.3	53	58.9	
Age							
60-74 years	13	43.3	44	73.3	57	63.3	
≥75 years	17	56.7	16	26.7	33 a	36.7	
Ethnicity							
Malay	10	33.3	20	33.3	30	33.3	
Chinese	15	50.0	30	50.0	45	50.0	
Indian	5	16.7	10	16.7	15	16.7	
Marital Status							
Married	21	70.0	45	75.0	66	73.3	
Widowed	9	30.0	15	25.0	24	26.7	
Education Level							
No formal education	7	23.2	3	5.0	10	11.1	
Primary/Secondary	23	76.7	57	95.0	80 ь	88.9	
school/Tertiary							
Occupation Status							
Not working/Housewife	13	43.3	32	53.4	45	50.0	
Retired	15	50.0	23	38.3	38	42.2	
Working	2	6.7	5	8.3	7	7.7	
Living Arrangement							
Alone	1	3.3	0	0.0	1	1.1	
Spouse/Children	26	86.6	58	96.6	84	93.3	
Old folks home/Others	3	10.0	2	3.3	5	5.5	
Health Profiles							
Chronic and acute disease)							
Diabetes mellitus	12	40.0	29	48.3	41	45.6	
Hypertension	13	43.3	45	75.0	58 ª	64.4	
Heart disease	3	10.0	14	23.3	17	18.9	
Respiratory disease	1	3.3	5	8.3	6	6.7	
Digestive tract disease	3	10.0	13	21.7	16	17.8	
Blood disease	0	0.0	3	5.0	3	3.3	
Musculoskeletal disease	8	26.7	26	43.3	34	37.8	
Visual impairment	13	43.3	35	58.3	48	53.3	
Hearing impairment	5	16.7	5	8.3	10	11.1	
Dental problem							
Dentures	12	40.0	14	23.3	26	28.9	
No teeth	7	23.3	3	5.0	10	11.1	
Others (what does this mean??)	2	6.7	2	3.3	4 °	4.4	
Chewing problem	_	10.5	_		_		
No teeth	3	10.0	2	3.3	5	5.6	
Dentures problem	6	20.0	4	6.7	10	11.1	
Gum disease	0	0.0	2	3.3	2	2.2	
Others	1	3.3	0	0.0	1	1.1	
Geriatric Syndromes		=0.5		22.5		00.6	
Fall	15	50.0	20	33.3	35	38.9	
Incontinence	11	36.7	6	10.0	17 a	18.9	
Immobility	8	26.7	5	8.3	13 в	14.4	

 $^{^{\}rm a}$ p<0.01, significant difference between groups (Pearson Chi Square Test) $^{\rm b}$ p<0.05, significant difference between groups (Fisher's Exact Test)

^cp<0.01, significant difference between groups (Fisher's Exact Test)

Table 2. Anthropometric profiles, EdFED-Q scores, functional status scores and Zarit Burden Interview scores of subjects [Presented as mean ± SD]

Characteristics	Subjects with dementia (n=30)	Subjects without dementia (n=60)	
Anthropometric Profiles			
Weight (kg)	54.0 ± 12.7	62.7 ± 13.1 a	
Height (m)	156.4 ± 9.0	157.1 ± 8.2	
Body Mass Index (kg/m²)	22.1 ± 4.8	$25.2 \pm 4.8^{\mathrm{b}}$	
EdFED-Q			
Score	4.90 ± 4.37	0.53 ± 1.08 °	
Functional Status			
ADLs Score	2.93 ± 2.36	5.70 ± 0.74	
IADLs Score	0.97 ± 1.56	4.08 ± 1.38	
Functional Status Score	3.70 ± 3.77	9.78 ± 1.78 °	
Zarit Burden Interview			
Score	32.93 ± 21.11	11.10 ± 9.61 °	
Scale	2.03 ± 1.03	1.13 ± 0.34 °	

^a p<0.01, significant difference between groups (Mann-Whitney U Test)

Table 3. Energy and nutrient intake of subjects [present as mean ± SD and % from the Malaysian Recommended Nutrient Intake (RNI)]

Nutrient (unit)	Subjects with dementia (n=30)		Subjects without dementia (n=60)		
	Mean ± SD	% RNI	Mean ± SD	% RNI	
Energy (kcal/d)	1261 ± 259	66.9	1237 ± 238	66.0	
Carbohydrate (g/d)	181.9 ± 41.2		178.0 ± 38.9		
Protein (g/d)	0.9 ± 0.3	84.9	48.3 ± 12.1	89.0	
Fat (g/d)	38.9 ± 9.2		37.2 ± 8.5		
Vitamin A (ug RE/d)	527.7 ± 220.9	87.2	502.5 ± 190.3	83.4	
Thiamin (mg/d)	0.9 ± 0.4	76.8	0.8 ± 0.3	71.7	
Riboflavin (mg/d)	1.2 ± 0.6	96.2	1.1 ± 0.4	89.7	
Niacin (mg NE/d)	10.7 ± 6.2	73.0	10.3 ± 4.2	69.0	
Vitamin C (mg/d)	67.4 ± 32.4	97.9	70.0 ± 51.0	101.5	
Calcium (mg/d)	372.7 ± 157.4	38.6	343.6 ± 156.4	37.0	
Ferum (mg/d)	11.0 ± 3.6	40.7	2.5 ± 1.1	47.0	
Zinc (mg/d)	2.2 ± 0.8	40.7	2.5 ± 1.1	47.0	

DISCUSSION

This study is likely the first of its kind in Malaysia to report that feeding problems and functional disabilities influence caregiver burden among patients with and without dementia. The high prevalence of feeding problems among patients with dementia was consistent with those found in previous studies (Chang & Roberts, 2008a; Hung & Chaudhury, 2011). As expected, the present study found that patients with dementia were also more dependent than those

^b p<0.01, significant difference between groups (Independent t Test)

[°] p<0.05, significant difference between groups (Mann-Whitney U Test)</p>
ADL- Activities of Daily Living; IADL- Instrumental Activities of Daily Living

Table 4. Assessment of Edinburgh Feeding Evaluation in Dementia Questionnaire (EdFED-Q) of subjects [Presented as n (%)]

EdFED-Q	Subjects with dementia (n=30)		Subjects without dementia(n=60)		P value
Supervision					0.000 a
Ŷes	18	60.0	1	1.7	
No	12	4 0.0	59	98.3	
Physical help					0.000 a
Yes	15	50.0	2	3.3	
No	15	50.0	58	96.7	
Food spillage					0.000 a
Yes	16	53.3	4	6.7	
No	14	46.7	56	93.3	
Leave food on plate					0.000 a
Yes	14	46.7	2	3.3	
No	16	53.3	58	96.7	
Refuse to eat					0.124
Yes	11	36.6	12	20.0	
No	19	63.3	48	80.0	
Turn his head away while being fed b					0.015 в
Yes	6	20.0	2	3.3	
No	24	80.0	58	96.7	
Refuse to open mouth					0.002 a
Yes	7	23.3	1	1.7	
No	23	76.7	59	98.3	
Spit out the food					0.000 a
Yes	7	23.3	0	0.0	
No	23	76.7	60	100.0	
Leave his mouth open					0.041 b
Yes	4	13.3	1	1.7	
No	26	86.7	59	98.3	
Refuse to swallow					0.011 b
Yes	4	13.3	0	0.0	
No	26	86.7	60	100.0	

^a p<0.01, ^b p<0.05. Fisher's Exact Test

without dementia in carrying out their daily living activities, such as bathing, dressing and toileting. In a review paper by Wilms, Riedel-Heller & Angermeyer (2007), patients with dementia were found to face several difficulties in performing activities that need a lot of movement. In this study, higher IADLs, ADLs and functional status scores were noted in subjects without dementia. These findings are in line with the findings of the study among the non-institutionalised elderly in Singapore (Niti et al., 2007), where

IADLs status in patients without dementia was better than patients with dementia.

This study revealed that caregivers burden of subjects with dementia was two to three times more than that of the caregivers of those without dementia. Findings showed that there was a significant statistical difference in burden of care between the demented elderly and elderly without cognitive problems, which had not been emphasised by previous studies (Andren & Elmstahl, 2008; McCurry et al., 2009).

Table 5. Socio-demographic characteristics of caregivers [Presented as n (%)]

Characteristics	Caregivers for subjects with dementia (n=30)		Caregivers for subjects without dementia (n=60)		Total (n=90)	
Gender						
Men	10	33.3	20	33.3	30	33.3
Women	20	66.7	40	66.7	60	66.7
Marital Status						
Single	5	16.6	15	25.0	20	22.2
Married	25	83.3	45	<i>7</i> 5.0	70	77.8
Education Level						
No formal education	1	3.3	0	0.0	1	1.1
Primary/Secondary	29	96.7	60	100.0	89	98.9
school/Tertiary						
Occupation Status						
Not working/ housewife	7	23.3	20	33.3	27	30.0
Retired	9	30.0	9	15.0	18	20.0
Working	14	46.7	31	51.7	4 5	50.0
Sources of income						
Pension	10	33.3	8	13.3	18	20.0
Salary	14	46.7	34	56.7	48	53.3
From children	5	16.7	8	13.3	13	14.4
Others	1	3.3	10	16.7	11	12.2
Type of Caregiver's Relationship						
Spouse	11	36.7	17	28.3	28	31.1
Children	15	50.0	37	61.7	52	57.8
Relatives	1	3.3	0	0.0	1	1.1
Others	3	10.0	6	10.0	9	10.0
Caregiving Duration						
<12 hours	17	56.6	58	96.7	7 5	83.3
>12 hours	13	43.3	2	3.3	15 a	16.7

^{*} p<0.01, significant difference between groups (Fisher's Exact test)

Table 6. Relationship between caregivers' burden score and duration of diagnosis, economic status, duration of care, age, Edinburgh Feeding Evaluation in Dementia (EdFED) and functional status (n=30)

Univariate	Caregivers'	burden score
	r	P value
Duration of diagnosis	0.283	0.130
Economic status (how was the RM value estimated?)	-0.200	0.289
Duration of care	0.311	0.095
Age	-0.072	0.707
Edinburgh Feeding Evaluation in Dementia	0.405	0.027ª
Functional status score	-0.475	0.008^{b}

^a p<0.05, Spearman correlation test; ^b p<0.01, Spearman correlation test

Caregiver burden has been reported to be associated with caregiver's characteristics (Rosdinom *et al.*, 2011; Lim *et al.*, 2008). Interestingly, this study has shown that caregiver burden was influenced by feeding problems and functional disability of elderly subjects.

The most common feeding problems occurred among patients with dementia were the need for supervision and physical help during mealtime and spillage during feeding. Hence, caregivers have to spend extra time to keep an eye on the patients during mealtimes. Chang & Roberts (2011) emphasised that those patients who faced difficulty during feeding required physical assistance from their caregivers. Feeding problems are a concern in geriatric care as it will lead to an inadequate energy intake and malnutrition. Caregivers should be educated on provision of energy and nutrient dense foods to prevent malnutrition and further deterioration of subjects' mental and physical health. As mentioned earlier, this study had also shown that functional disability among subjects with dementia increased the caregiver burden. The most common functional disabilities observed among subjects with dementia in this study were bathing and clothing for ADL and shopping, transporting and taking medicine for IADL. According to Shiau et al. (2006), ADL performance was greatly influenced by cognitive impairment among the elderly with dementia. Poor functional status of carerecipients directly related to higher caregivers' burden (Huang et al., 2012) and increased caregiving time and feelings of being socially isolated (Chen et al., 2010). Caregivers have to spend time looking after the patients' needs and this may not be acceptable to the younger generation who place priority on their own social life and needs. There is a need to embark on psychosocial intervention to assist and empower caregivers in performing their task effectively with minimal stress.

Although this study was conducted on a relatively small sample size that would not be sufficient to generalise the findings to other Asian countries, the study has investigated the influence of feeding problems and functional status on caregiver burden through a comparative cross-sectional study. Future studies should adopt a multi-centre recruitment approach, involving biomarkers of nutrient deficiency and also an assessment of dementia severity.

CONCLUSION

Underweight, feeding problems and functional disabilities were higher among patients with dementia as compared to those without dementia, leading to a higher caregiver burden to the respective caregivers. Thus, caregivers should be educated on methods to overcome such problems through a psychosocial and nutrition intervention programme which may indirectly help to reduce the level of caregiver burden and further increase the quality of life of both carers and patients with dementia.

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