ORIGINAL PAPER

Sociodemographic Profiles of Caregivers and Their Association with Burden of Care in Dementia

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Abstract

Caring for a family member with dementia is associated with distress and several caregiver factors are known to be determinants of burden of care. Objective: To determine the relationship between the caregivers' sociodemographic variables and their perceived burden of care. Methods: Patients diagnosed as having dementia with their caregivers were selected through a non-randomised sampling method from the psychogeriatric and memory clinics in Universiti Kebangsaan Malaysia Medical Centre and Hospital Kuala Lumpur. Burden of care was assessed using the Zarit Burden Interview. Results: Age, gender, educational achievement, ethnicity and kinship of the 65 caregivers did not show any significant statistical difference in relation to their perceived burden. Conclusion: Burden in caring after patients with dementia was not significantly determined by the sociodemographic characteristics of their caregivers.

Keywords: Dementia, Burden of care, Caregivers, Zarit Burden Interview

Introduction

Dementia is a degenerative illness characterized by loss of ability to remember, think abstractly, poor judgment and personality changes. As a result, patients with dementia will lose the functional capacity for independence and personal care, and will require major assistance in their daily activities. It is estimated that the number of people with dementia in the Asia Pacific region will escalate from 13.7 million in 2005 to 64.6 million in 2050[1].

Similarly, as the population of the older people in Malaysia increases, the population of people with dementia will also increase. Therefore, caregiving has become an important social issue. Caring for someone with dementia can be stressful and is associated with high level of caregiver burden. The term "caregiver burden" is used to describe the extent to which caregivers perceive their social life, physical health, emotional well-being and financial status as being affected as the result of providing care. It is known that caring for someone

with dementia is associated with a higher level of stress as compared to caring for someone with functional impairment as a result of chronic physical illness. Caregivers' poor ability to cope with patients' behavioural problems and the lack of emotional support are associated with high level of caregiver burden and increased risk of patient institutionalization[2]. Caregiver burden can affect the quality of caregiving and caregivers' own quality of life.

Caregiver burden is determined by multiple determinants interacting in complex circular ways[3]. Patient's and caregiver's sociodemographic variables are the two main factors that are well studied in many literatures. Female caregivers tend to report higher level of burden compared to male caregivers[4-6]. Daughters seem to report experiencing greater burden than sons.[7-10] Caregiver-patient relationship is another important contributor to caregiver burden. Closer kinship to the patient imposed a heavier burden.[11] Recent studies have also shown that culture and ethnicity influence the care-giving process. A study by Chou et al.[12] found that, "filial obligation" as a cultural norm, reduced caregiver burden in caregivers of relatives with dementia in Taiwan. Choo W.Y., et al[13] did a study of 70 caregivers of patients with dementia in Malaysia and found that Chinese caregivers had higher level of burden compared to Indian and Malay caregivers. There was a range of mediating variables that played important role in predicting caregiver burden. Informal support, in particular, assistance from family members, was significantly associated with a lower burden perceived by caregivers. Low educational achievement, the elderly and spouse caregivers are often targets for psychoeducation about the different types of dementia despite lack of evidence to show

that knowledge about dementia is effective in reducing caregiver burden or distress.[14-15] This research aims to study the sociodemographic profile of local caregivers of people with dementia and determine its association with burden of care.

Methods

Patients
A cross-sectional study was conducted on a dyad group of elderly outpatients diagnosed as Dementia according to the DSM IV[16], and their caregivers attending the psychogeriartic clinics and memory clinics of University Kebangsaan Malaysia Medical Center (UKMMC) and Hospital Kuala Lumpur (HKL). The memory clinics were set up for the assessment and treatment of cognitively impairment. They are run by 2 psychogeriatricians, 1 in a university hospital and the other in a Government hospital. These hospitals serve as tertiary medical centers, serving a large proportion of the population in the capital city of Malaysia, Kuala Lumpur.

Exclusion criteria for patients included those under the custodial care of private nursing homes or Government-run old folks homes. These residential homes lack trained staffs needed for close supervision of patients and accurate reporting of patients' conditions.

Caregivers
Inclusion criteria were caregivers who were able to read and write, and must be aged 18 and above. In this study, a "caregiver" is defined as:
1) Someone who attends to the patient for at least 12 hours a day, almost everyday including housemaid,
2) Someone who provides care for the patient, e.g assistance with activities of daily living, managing finances,

administrating medication, and providing emotional support.

Domestic helpers are included if they were able to fulfill the above criteria.

Instruments

Two sets of demographic questionnaires for the patients and their caregivers, and the Zarit Burden Interview[17] were used. The latter is designed to assess the level of burden in caregivers of patients with dementia, focusing on caregivers' health, social life, finances, psychological well-being and their relationship with the patients. It is a 22-item scale scored on a 5-point sliding scale, ranging from 0 = 'never' to 4 = 'nearly always'. The scores on the items are summed for the total score, with higher scores indicating higher burden. It has been translated into several languages and validation studies in Asian populations have shown it to be a valid and reliable tool in measuring the burden of caregivers of patients with dementia.[20-23] The permission to use and translate this instrument into the local language Bahasa Malaysia, had been obtained from the author, Steven H. Zarit. Patients and their caregivers were interviewed in a separate room within the clinic to ensure confidentiality. Informed consent for this study was obtained from the caregivers and the patients themselves whenever possible.

Statisical Analysis

Data was analysed using the Statistical Package for Social Studies (SPSS) software version 12. For analysis, the significant level of p=0.05 was chosen at the 95% confidence interval.

Multiple linear regression analysis was used to examine the association between the significant sociodemographic and clinical variables, and Burden Interview scores.

Results

There were 65 suitable patients and their caregivers selected into the study.

1) **Patient factors**
   More than three-quarters of the 65 selected patients were female (76.9%), with the mean age of 74.11 ± 7.47 years. More than half were Malays, about half of them were either widowed, divorced or separated, had a mean duration of illness of 4.92 ± 3.12 years and about a quarter had no formal education (24.6%) (Table 1).

Table 1: Sociodemographic characteristics of patients with dementia

Variable		Frequency (n)	Percentage (%)	Mean ± SD
Age (years)	61 – 70	22	33.8	
	71 – 80	28	43.1	74.11 ± 7.47
	81 – 90	15	23.1	
Gender	Male	15	23.1	
	Female	50	76.9	

Race	Malay	34	52.3
	Chinese	24	36.9
	Indian	7	10.8
Marital status	Single	4	6.2
	Married	28	43.1
	Divorced/separated	6	9.2
	Widowed	27	41.5
Education	No formal education	16	24.6
	Primary	34	52.3
	Secondary	13	20.0
	Tertiary	2	3.1

| Duration of illness (years) | | 4.92 ± 3.12 |

2) Care giver factors

Most of the caregivers were in the middle age group (mean age of 49.23 years), about two-thirds (66.2%) were female, more than half (55.4%) were Malays, majority were married (81.5%), mostly were patients' own daughters (40%), still employed (55.4%), and enjoyed shared-caregiving with other family members (58.5%). Most of them had educational level up to secondary school level (43.1%) and reported no financial difficulties (81.5%) (Table 2).

Table 2: Sociodemographic characteristics of caregivers

Variables		Frequency (n)	Percentage	Mean ± SD
Age (yr)	20 – 39	13	20	
	40 – 59	41	63	49.23 ± 12.17
	60 – 79	10	15.4	
	> 80	1	1.5	
Gender	Male	22	33.8	
	Female	43	66.2	
Race	Malay	36	55.4	
	Chinese	23	35.4	
	Indian	6	9.2	

Marital status	Single	9	13.8	
	Married	53	81.5	
	Divorced/separated	2	3.1	
	Widowed	1	1.5	
Education	No formal education	1	1.5	
	Primary	11	16.9	
	Secondary	28	43.1	
	Tertiary	25	38.5	
Caregiving duration				2.63 ± 1.11
Type of caregiver's relationship	Husband/wife	10	15.4	
	Daughter	26	40.0	
	Son	16	24.6	
	Daughter in law	4	6.2	
	Sibling	2	3.1	
	Maid	4	6.2	
	Others	2	3.1	
Employment	Employed	36	55.4	
	Unemployed	29	44.6	
Financial status	Problematic	12	18.5	
	Non problematic	53	81.5	
Shared/unshared caregiving	Shared caregiving	38	58.5	
	Unshared caregiving	27	41.5	

Statistical analysis showed there was no significant difference between the race group, marital status, educational level of the caregiver, relationship between patient and caregiver, and Burden Interview scores (ANOVA; p race group = 0.730, p marital status = 0.717, p educational level = 0.020). The type of caregivers' relationship with the patient did not influence caregiver burden. Even though son-in-law reported to have highest level of burden followed by husband or wife and daughter, the difference in Burden Interview score between the different groups was not found to be statistically significant (Table 3).

Table 3: Relationship between caregiver's relationship with the patient and Burden Interview score

Variables	Mean	Test	p
Husband / wife	55.00 ± 18.34		
Son	53.60 ± 16.43		
Daughter	55.19 ± 14.97		
Son in law	60.00 ± 0.00	ANOVA	
Daughter in law	46.00 ± 18.53		0.806
Maid	48.75 ± 7.68	$F = 0.533$	
Sibling	65.00 ± 16.97		
Others	42.50 ± 23.33		
Total	53.66 ± 15.65		

Further statistical analysis on the caregiver sociodemographic factors and levels of burden revealed no significant difference in the Burden Interview scores between male and female caregivers ($t = 0.492$, $p = 0.624$), employed and unemployed caregivers ($p = 0.357$), caregivers with or without financial problems ($p=0.220$) and among those who shared or did not share the caregiving task ($p= 0.578$). Younger caregivers were found to have higher degree of burden but this finding was not statistically significant ($r = -0.052$, $p = 0.679$). Caregivers with shorter duration of caregiving also reported higher level of feeling of burden but analysis also did not show any statistical significance ($r = -0.073$, $p = 0.561$).

Discussion

All patients in this study were aged 69 years and above as the prevalence of dementia tend to be higher in the elderly age group. There was a preponderance of female patients in this sample. This might be due to a longer life expectancy in women as compared to men. There were more Malay patients than other races and the ethnic distribution in this sample reflected the distribution of the different ethnic groups in this country. Almost all of the Malays in this country are Muslims and their perception of burden is seen as being less stressful as compared to other racial groups, especially when caring after their own parents or spouses. One of the principle teachings in Islam is to be respectful, patient and tolerant when dealing with the sick and the elderly and this forms a common basis for filial piety. Unfortunately, this study could not prove any significant statistical difference in burden of care among the different ethnic groups.

In this study, the mean duration of patients' illness was about 5 years with a wide range of duration of illness (between 6 months to 16 years). More than half of the patients had illness of less than 6 years duration. There were no significant differences in caregiver burden between the male and female caregivers and the relationship between the caregiver and patient. A local study on burden of care among the caregivers of patients with Parkinson disease also showed less burden among the Malay caregivers and

similarly, no significant relationships between the caregivers' gender, duration of care-giving and kinship, and their perceived burden.[22] These findings differ from a study which found that spouses experienced heavier burden compared to children and generally a closer kinship to the patient imposed heavier burden of caregiving11. In a Turkish study by Karlikaya et al, (2005)[23], there was no significant difference for most of the demographic factors but the mean Zarit Interview score was higher in the spouse or adult child, compared to other relatives as the caregiver. The closer the caregiver is to the patient, the care giving emotionally gets harder and the burden is high.[25]

Other factors such as caregivers' age and education level were also not found to be significantly associated with caregiver burden. An important reason for the disparity in the findings was the small sample size which could affect the power of this study. Another reason might be due to ignorance or high tolerance among local caregivers towards symptoms of dementia. Some families have accepted symptoms of dementia as part of normal ageing, thus reducing their own conflicts of ambivalency, and sense of helplessness and frustration over this devastating illness.

In this study, housemaids comprised of 6.2% of caregivers and there was no significant association found between the hired caregiving and caregiver burden. The non significant finding might also be due to the small sample size of study subjects. Ideally the use of maids as caregivers in this study should be excluded as the Zarit Burden Interview is designed only for relatives and unpaid caregivers. The housemaids would have responded to the Burden Interview slightly different from the patients' own relatives as they were paid to do work and were not as emotionally attached to the patients. However, in this study the authors had decided to include housemaids as caregivers because in Malaysia, the maids live together with the families and play a very important role as caregivers. Apart from doing household chores, their other duties also include taking care of babies and small children, and looking after elderly family members at home. Having a maid as caregiver is a better option for many families as it is more economical, reassuring and culturally acceptable as compared to sending them to the nursing homes.

However, the findings in this study are not reflective of the whole population of people with dementia in the country. This small sample of outpatients is only a fraction of a bigger proportion in the community. These findings cannot be generalised to all other outpatients in other hospitals in the country as this study involved only a small group of patients selected by convenience sampling in 2 urban hospitals. The authors believe that dementia is still being under-diagnosed by many doctors, including the primary health care clinicians in the rural as well as urban regions of the country. Public awareness plays a major role in the early detection and treatment of dementia. Unfortunately, most people still associate some of the symptoms of dementia as part of normal ageing. Delay in seeking treatment is not only a costly mistake but it results in more severe symptoms as the illness progresses, which will ultimately contribute to caregiver distress, premature institutionalization and higher usage of costly psychotropic medications.[22] Eventhough this study is not able to show significant associations between caregiver demographic factors and burden of care, it is still important to identify caregivers with significant levels of burden and provide appropriate interventions to alleviate it.

Conclusion

In this study, burden of care in patients with dementia was not significantly determined by the sociodemographic characteristics of their caregivers, including kinship and ethnicity. Other factors suspected to be related to burden, such as behavioral problems or cognitive impairment in patients should also be studied in future.

Acknowledgment

The authors would like to express their gratitude to the nursing staffs of both hospitals for their assistance in making this study possible. There is no conflict of interest in the conduct of this study.

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