

**A STUDY ON BURDEN AMONG CAREGIVERS OF PATIENT WITH  
DEMENTIA IN HOSPITAL UNIVERSITI SAINS MALAYSIA  
KELANTAN**

**BY**

**DR TUAN ZAILINA BT TUAN NGAH**

**Dissertation Submitted In  
Partial Fulfillment Of The Requirements  
For The Degree Of Master of Medicine  
(Family Medicine)**

**May 2008**

## ACKNOWLEDGEMENT

I would like to express my appreciation to Dr Juwita Shaaban, Head of Department Family Medicine of Medical Sciences, Health Campus Kubang Kerian, Universiti Sains Malaysia for her guidance and immeasurable help throughout the preparation of this dissertation. As my supervisors, her encouragement, support and comments have enabled me to complete this study.

I would also like to express my sincere appreciation and gratitude to Dr Atul Prasad, former lecturer from Medical Department, Dr Azidah abd Kadir lecturer from Family Medicine Department , Dr Rohayah bt Husain and Dr Asrenee lecturers from psychiatric Department, School of Medical Sciences, Health Campus Kubang Kerian, Univesiti Sains Malaysia for their invaluable advice and help in conducting this study.

I am also would like to extend my appreciation to Dr Sarimah Abdullah from Biostatistic Unit, Department of Community Medicine, HUSM for her guidance in statistical analysis.

Last but not least, I would like to express my utmost gratitude to my husband Che Aniru bin Che Yaakub, my two sons Che Ammar Danial and Che Imran Hakeem, my two daughters Che Nabila Farhanah and Che Deena Syakila for their patience and understanding throughout the study

# TABLE OF CONTENTS

	<b>Pages</b>
<b>Acknowledgement</b>	ii
<b>Table of contents</b>	iii
<b>List of tables and figures</b>	vi
<b>Abbreviations</b>	vii
<b>Abstract</b>	
Bahasa Malaysia	viii
Bahasa Inggeris	x
<b>CHAPTER 1 INTRODUCTION</b>	
1.1 Diagnosis of Dementia	1
1.2 Clinical Features of Dementia	3
1.3 Types of Dementia	4
1.4 Course and Prognosis	5
1.5 Rationale of this study	5
<b>CHAPTER 2 LITERATURE REVIEW</b>	
2.1 Burden of Dementia	7
2.2 Caregiver Burden	8
2.3 Caregiver Depression	11
<b>CHAPTER 3 OBJECTIVES</b>	
3.1 General Objectives	15
3.2 Specific Objective	15

## **CHAPTER 4 METHODOLOGY**

4.1	Study area	16
4.2	Study Design	16
4.3	Sample	17
4.3.1	Inclusion Criteria	17
4.3.2	Exclusion Criteria	17
4.4	Sample Size	17
4.5	Sampling Method	20
4.6	Research Instruments	20
4.7	Method of Data Collection	24
4.8	Validation of Questionnaires	25
4.9	Ethical consideration	25
4.10	Definitions of Variables	25
4.11	Statistical analysis	27
4.12	Flow chart	29

## **CHAPTER 5 RESULTS**

5.1	Sociodemographic characteristics of dementia patients	30
5.2	Sociodemographic characteristics of caregivers	32
5.3	Level of burden among caregivers	34
5.4	Depression among caregivers	34
5.5	Relationship of caregiver sociodemographic characteristics and ZBI Scores	35

<b>CHAPTER 6 DISCUSSION</b>	
6.1 Sociodemographic Characteristics of the Dementia Patients	38
6.2 Sociodemographic Characteristics of the Caregivers	40
6.3 Level of burden among caregivers	43
6.4 Depression among caregivers	44
6.6 Relationship between burden and caregiver sociodemographic characteristics	45
<b>CHAPTER 7 CONCLUSIONS</b>	51
<b>CHAPTER 8 LIMITATIONS</b>	52
<b>CHAPTER 9 RECOMMENDATIONS</b>	54
<b>CHAPTER 10 REFERENCES</b>	55
<b>APPENDICES</b>	
Appendix I Consent Form	68
Appendix II Soal Selidik Pesakit	72
Appendix III Soal Selidik Mengenai Penjaga	73
Appendix IV Zarit Burden Interview (English version)	75
Appendix V Zarit Burden Interview (Malay version)	77
Appendix VI Brief Patient Health Questionnaire (PHQ-9)	79
Appendix VII Certificate of Ethical Approval	81

## LIST OF TABLES AND FIGURES

<b>List of Tables</b>		<b>Page</b>
Table 1	Sociodemographic characteristics of dementia patients	32
Table 2	Sociodemographic characteristics of caregiver	34
Table 3	The level of burden in caregivers	35
Table 4	Distribution of Brief PHQ-9 Scores among caregivers	36
Table 5	The relationship of caregiver sociodemographic characteristics and ZBI scores	38
Table 6	Post hoc sidak analysis	39
 <b>List of Figures</b>		
Figure 1	Flow chart of this study	30

## ABBREVIATIONS

HUSM	Hospital Universiti Sains Malaysia
KPP	Klinik Perubatan Keluarga
KRK	Klinik Rawatan Keluarga
PHQ-9	Patient Health Questionnaire-9
SD	Standard deviation
SPSS	Statistical package for social science
ZBI	Zarit Burden Interview

## **ABSTRAK**

### **KAJIAN MENGENAI BEBAN DI KALANGAN PENJAGA PESAKIT DEMENTIA DI HOSPITAL UNIVERSITI SAINS MALAYSIA.**

#### **Objektif**

Kajian mengenai beban di kalangan penjaga pesakit Dementia di Hospital Universiti Sains Malaysia dijalankan untuk mengenalpasti tahap beban di kalangan penjaga dan untuk menilai kemungkinan factor-faktor berisiko yang berkaitan dengan tahap beban yang tinggi.

#### **Metodologi**

Seramai 150 penjaga kepada pesakit Dementia telah ditemuramah. Peserta dipilih dari Klinik Rawatan Keluarga(KRK), Klinik Pakar Perubatan dan Klinik Psikiatrik di Hospital Universiti Malaysia. Penjaga di nilai mengenai bebanan menjaga pesakit dementia melalui Zarit Burden Interview. Penjaga juga disaring penyakit kemurungan dengan menggunakan soalselidik Brief PHQ-9.

#### **Keputusan**

69.3% daripada penjaga mengalami beban yang sedikit, 28.0% mengalami beban sederhana dan 2.7% mengalami beban yang teruk. 17.3% daripada penjaga skor PHQ-9, 5 dan lebih menunjukkan kemungkinan kemurungan di dalam kajian ini. Hubungan factor sosio demographic penjaga dengan beban yang didapati signifikan adalah tahap



pendidikan penjaga ( $p < 0.05$ ) dan tanggungjawab penjaga terhadap pesakit ( $p < 0.05$ ). Pendidikan primer mengalami lebih beban berbanding pendidikan sekunder ( $p < 0.05$ ) dan tertiary ( $p < 0.05$ ). Menjaga pesakit sepenuh masa dan bergilir menjaga pesakit dengan adik beradik mengalami lebih beban berbanding penjaga yang bertanggungjawab untuk bantuan kewangan, pengangkutan dan lain-lain ( $p < 0.05$ ).

### **Kesimpulan**

Faktor berkaitan dengan penjaga pesakit dementia seperti tahap pendidikan dan tanggungjawab penjaga kepada pesakit mesti di ambil kira didalam penilaian beban di kalangan penjaga. Saringan kemurungan juga penting di kalangan penjaga .

## ABSTRACT

### A STUDY ON BURDEN AMONG CAREGIVERS OF PATIENT WITH DEMENTIA IN HOSPITAL UNIVERSITI SAINS MALAYSIA

#### **Objective**

Study on burden among caregivers of patient with dementia in Hospital Universiti Sains Malaysia was done to determine the degree of burden among caregivers of dementia patient and to evaluate the possible risk factors associated with those with higher burden.

#### **Material and Method**

A total of 150 of caregivers of dementia patients were interviewed. Participants were recruited from Klinik Rawatan Keluarga (KRG), Klinik Pakar Perubatan and Psychiatric clinic, HUSM. Caregiver was assessed for level of burden by Zarit Burden Interview. Caregiver was also screened for depression with PHQ-9 questionnaire.

#### **Results**

69.3% of caregiver experienced mild burden, 28.0% experienced moderate burden and 2.7% experienced severe burden. 17.3% of caregivers scored 5 or more on PHQ-9 suggest of possible depression in this study. The significant association between caregiver sociodemographic characteristic and burden was caregiver level of education ( $p<0.05$ ) and caregiver responsibilities ( $p<0.05$ ) with caregiver burden. Primary level of education experienced more burden than those of secondary ( $p<0.05$ ) and tertiary level of

education ( $p < 0.05$ ). Caregiving full time and sharing care with siblings experienced more burden than those who were responsible for financial support, transport and other ( $p < 0.05$ ).

### **Conclusion**

Factors related to caregivers of dementia patients such as caregiver education and relationship, should be taken into account in the evaluation of caregivers' burden. Screening of depression among the caregivers is also important.

## **CHAPTER 1: INTRODUCTION**

Dementia is a condition characterized by loss of intellectual abilities that is sufficient to hinder social and occupational function as well as activities of daily living (Gustafson L 1996).

An estimated 5 to 10 percent of the adult population aged 65 years and older is affected by a dementing disorder. The prevalence doubles every 5 years among people in this age group (Jorm et al, 1987). In 1998, World Health Organization estimated that there are around 29 million people with dementia worldwide (WHO 1998). This number is expected to rise to 55 million by 2020. This is due to the rapid ageing of populations. With the doubling population over the next 25 years, it is anticipated that the burden of dementia caregiving will increase correspondingly.

### **1.1 Diagnosis of Dementia**

The Royal College of Physicians defines dementia as the acquired global impairment of higher cortical functions including memory, the capacity to solve problems of day-to-day living, the performance of learned perceptuo-motor skills, the correct use of social skills, all aspects of language and communication and the control of emotional reaction, in the absence of clouding of consciousness. The condition is often progressive though not necessarily irreversible (Royal College of Physicians 1982).

The diagnosis of dementia can be made according to the DSM-IV classification (American Psychiatric Association 1994) or using ICD classification (WHO 1994).

#### DSM-IV classification

A. The development of multiple cognitive deficits manifested by:

1. Memory impairment (impaired ability to learn new information or to recall previously learned information)
2. One (or more) of the following cognitive disturbances:
  - a. aphasia (language disturbance)
  - b. apraxia (impaired ability to carry out motor activities despite intact motor function)
  - c. agnosia (failure to recognise or identify objects despite intact sensory function)
  - d. disturbance in executive functioning (i.e. planning, organising, sequencing, abstracting)

B. The cognitive deficits in criteria A1 and A2 each causes significant impairment in social and occupational functioning and represents a significant decline from previous level of functional.

Based on the ICD classification :

Dementia is a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement. Consciousness is not clouded. Impairments of cognitive function are accompanied and occasionally preceded by deterioration in emotional control, social behaviour or motivation.

## **1.2 Clinical Features of Dementia**

Features of dementia include behavioural and psychological symptoms. These symptoms can occur at any stage of the dementing illness (CPG Dementia 2003). The behavioural and psychological symptoms of dementia can be divided into 2 main groups:

**Behavioural problems** include:

- **Agitation**

This can present as physical agitation including pacing, restlessness, disinhibited behaviour, wandering, stereotyping or verbal agitation such as complaining , requesting for attention, exhibiting negativism, repeated questioning or phrasing and screaming

- **Aggression**

Aggression can be physical such as hitting, pushing, tearing or crying, spitting, kicking, scratching and biting or verbal such as threats, accusations, name-calling or obscenities

- Apathy

Apathy is a common behavioural problem in AD and related dementias, and may occur even in the absence of depression.

**Psychological symptoms include:**

- Psychosis (hallucinations, misperceptions and delusions).
- Depression
- Others (insomnia and anxiety)

Other associated features are changes in dietary habits and deficits in visuo-spatial functioning. The latter may lead them to underestimate risks involved in activities such as driving. Dementia is sometimes accompanied by motor disturbances such as gait disturbances, slurred speech and a variety of abnormal movements. Seizures and loss of sphincteric control can also occur.

### **1.3 Types of Dementia**

Dementia can be categorized according to the various causes depending on pathology, clinical presentations and additional symptoms (American Psychiatric Association 1994)

The categories include:

Dementia of the Alzheimer's Type or Alzheimer's disease accounts for 50 – 60% of all dementia cases. Vascular dementia can be seen in up to 15% of patients. Nineteen percent

of patients have either Lewy body dementia or dementia associated with Parkinson's disease (Shergill et al, 1994)

#### **1.4 Course and prognosis**

The mode of onset and subsequent course of dementia depend on the underlying aetiology. Dementia may be progressive, static or remitting. The reversibility of dementia depends on the underlying pathology, the availability and timely application of effective treatment. The natural history of the disease is that of a decline due to progressive damage to widespread areas of the brain (CPG Dementia 2003).

As the overall functional status deteriorates, the person's ability to adjust to changes in the environment deteriorates to such an extent that death ensues. Dementia shortens life expectancy; with estimates of median survival of 5 to 9.3 years (Wolfson C et al, 2001).

#### **1.5 Rationale of study**

1. Managing the burden of dementia is a challenge for patients' families and health-care professionals, with resultant high costs for society. Dementia is still perceived by many as a hopeless condition that is not amenable to intervention. By assessing the caregiver's level of burden, including the issue of depression, caregivers who are at high risk for physical and emotional problems can be identified.



2. By assessing the caregiver's level of burden, the physician can help the family members in anticipating changes, plan for role transitions, and arrange for education and support that is needed to provide care for dementia family members.
3. Majority of caregivers live with their demented relatives in whom the patient relies heavily upon their caregivers for what we know that there is no respite care available in Kelantan, therefore without understanding the caregiver burden will put the patients at home care risk.
4. This study can add to the limited data available regarding the burden among caregivers of demented patient in Malaysia.

## **CHAPTER 2 : LITERATURE REVIEW**

### **2.1 Burden of Dementia**

The features of dementia have been linked to numerous negative outcomes in caregivers, including psychological disturbances, physical health problems, relationship changes and social activity restrictions (Gwyther, 1986)

Given the characteristic cognitive, behavioural and effective losses associated with the progression of the disease, caring for relatives with dementia is assumed to be more difficult and burdensome than caring for loved ones with other chronic conditions and disabilities (Marcia et al, 1999).

Dementia is a problematic disease, not only within the scientific field, but also for the organization of health care. Among the problems caused by this disease, one of the foremost is the burden borne by the relatives of the demented persons. (Zarit SH, 1989)

It is becoming evident that caregivers have a role in the overall treatment outcome. Care recipients are benefit from having caregivers because they live longer, are less likely to be placed in nursing homes, and have better physical and psychological well being (Rabins, 1998). Caregivers also benefit to health care providers by being a link for the elderly patient who may forget, misinterpret, or be physically unable to implement medication regimens; by alerting the health care provider to problems that care recipient may have not mentioned; and ensuring compliance with medical interventions (Haley, 1997).

The quality of care they provided, however, will be compromised due to caregiver's physical health impairments, other family and work obligation, difficulty gaining access to community resources to assist with caregiving, and financial and time constraints (Fredman, 2001).

## **2.2 Caregiver Burden**

The burden of care giving, as defined by Zarit can be understood as the extent to which caregivers perceived their emotional or physical health, social life and financial status to be adversely affected as a result of caring for their relatives. (Hoffman RL, 1998)

Caregiver is defined as a family member who provide care for an elderly relative with dementia who needs assistance in performing activities associated with daily living either in terms of physically, financially, socially and psychologically.

Caregiver burden is mainly affected by two types of factors, patient variables and caregiver variables with the latter being the stronger predictor of caregiver outcomes. Patient variables have less impact on caregiver burden except for behavioral problems.

Caregivers find aggression compared with wandering, delusions and incontinence is the most distressing behavioral disturbance of patients with dementia. (Barbara et al., 2006). Other patient variables such as cognitive impairment, functional impairment, duration of

illness and severity of impairment do not show consistent association with caregivers' burden (Dunkin JJ and AHC,1998).

Caregiver variables, on the other hands, have much greater impact on burden. Caregiver variables include demographic variables such as caregiver's age, ethnicity, level of education, household income, social support, health status and relationship between the patient and caregiver (Haley, 1997).

Caregiver's age is indirect predictor as older caregivers report poorer health, which would determine burden. In term of gender, female caregivers tend to report higher level of burden than male caregivers in many studies (Dunkin JJ and A.HC,1998). A meta analysis of gender differences suggests that female caregivers perform more personal care tasks for their impaired relative, such as toileting and bathing, as well as more household chores, and these tasks may bear a stronger relationship to caregiver burden (Miller B, 1992)

Ethnicity as a predictor of outcome in caregiving has been a focus of research in recent years and has consistently been shown to be an important variable in understanding caregiving process. Local study found that Chinese and Indian were more highly burdened than Malays (Wan Yuen Choo et al., 2003).

Caregiver-patient relationship is an important contributor to overall caregiver burden. Current research found that spouse caregivers tend to report more burdens than adult

children while daughters in law are more vulnerable to stress than adult children or spousal caregivers (Gywether LP, 1998). Research suggests that spouses provide care with fewer supports and often in the face of tension when their expectations and plans differ from other family members. Spouses with more sense of control may be less likely to have depressive symptoms. Daughter and daughter in law caregivers may have different challenges. There may be conflicting demands between care of the parent, care of children and employment outside the home (Barbara et al., 2006)

Religion and spirituality may be important to many caregivers. African Americans commonly cope with caregiving through spirituality, expressing higher religiosity values and involvement than Euro-Americans. Moreover, it appears that African Americans not only appraise aspects of caregiving as less stressful than Euro-Americans, but they may also derive more benefit and meaning from the experience. (Barbara et al, 2006). Other demographic caregivers variables, the caregiver's level of education appear bear little relationship to outcome.

The availability of social support and network is important as it provides both instrumental and emotional support to caregivers. Caregivers with less social network and low satisfaction with the support they received were reported to have a significantly higher burden than caregivers with stronger social ties (Haley, 1997).

An accumulation of these pressures can threaten caregivers' ability to continue supporting the dementia sufferer at home. It is essential to identify patient impairments

that, via their effect on caregivers, put home care at risk. This knowledge would enable specific interventions to be designed for distressed caregivers.

### **2.3 Caregiver depression**

Caring for dementia can often have serious adverse health and personal consequences for caregivers. Depression is one of the most important potential adverse consequences for caregivers because it is commonly associated with poor quality of life, and is a risk factor for other adverse outcomes including functional decline and mortality (Kenneth et al, 2003).

Multiple studies (Livingstone et al., 1996, Rosenthal CJ et al., 1993, Teri L, Truax P, 1994) have shown that the incidence of depression in caregivers is high, ranging from 18 to 47 percent, and caregivers who are depressed experience higher degrees of burden (Susan, 2000).

Excessive stress could lead to increased psychiatric morbidity for caregivers. Gilleard et al (1984) found that the prevalence of psychological disturbance was high among caregivers, as shown by an increased score for the General Health Questionnaire (GHQ).

Family members giving care to a person with dementia are nearly twice as likely to have symptoms of depression compared with caregivers of non-demented people. They also have higher rates of chronic illness and are twice more likely to be using psychotropic

medications for depression or anxiety than people who are giving care to someone without dementia. (Canadian Study of Health and Aging, 1994).

The impact of caregiver burden is not limited to the caregivers themselves but had a direct effect on the care recipient well-being. Caregivers who are highly stressed are more likely to cause depression, abuse or neglect and institutionalization of care recipients (Fredman, 2001). This may be a direct consequence of caregiver's anger, inability to cope, care recipient's behavioural disturbance, lack of emotional support and social isolation (Haley et al., 1987).

The caregiver role is linked with psychological and physical morbidity which include higher than usual psychotropic drug use, alcohol, cigarettes, and mood-altering drugs (Fredman, 2001), poor self-rated health (Dunkin JJ and A. HC, 1998), impaired immune system, risk of cardiovascular disease and depression (Farran et al, 1997). Caregiver themselves report facing more stress, psychological problems, physical health problems, social isolation and family conflicts, than do persons who are not caregivers (Dunkin JJ and A. HC, 1998).

Informal caregivers of individuals with AD (Alzheimer's Disease) are one of our health care system's greatest resources and their task is not an easy one being fraught with psychological stress and physical exhaustion (Aadil Jhan Shah, 2007).

Several studies suggest that many caregivers are at risk of experiencing clinical depression (Gallant & Connel., 1997). Nearly half of the caregivers in some studies were

reported to meet diagnostic criteria for depression when structured clinical interviews were used (Cohen & Eisdorfer, 1988). There is also some evidence to suggest that a diagnosis of depression can be causally related to the caregiving situation. Dura and Kiecolt (1991), found that nearly one quarter of caregivers met the criteria for depression whilst in the caregiving role, although they had never been diagnosed with depression prior to their assumption of this role.

Previous study (Aadil Jhan Shah, 2007) suggests depression in caregiver's results from a complex interplay of factors that includes characteristics of the patient and caregiver, as well as cultural factors. There is strong evidence that difficult patient behaviors such as anger and aggressiveness influence caregiver depression, and these behavioral manifestations of dementia may be more influential than the degree of cognitive impairment.

Several studies suggest that caregivers with poorer health, or fewer financial resources, are at higher risk for depression. Some evidence also suggests that women and spousal caregivers are at higher risk for depression. A number of studies have suggested that caregivers of African-American patients are at lower risk for depression than caregivers of white patients (Aadil Jhan Shah, 2007)

Caregivers who maintain positive feelings towards their relative have a greater level of commitment to caring and a lower level of perceived strain, instead of carers who experience feelings of powerlessness, lack of control and unpreparedness have higher