DECLARATION

I hereby declared that the work produced in this thesis is of my own effort except for the quotations and summaries that I have duly acknowledged.

5th July 2015
DR NG CHAI NEE

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CERTIFICATION

This is to certify to the best of my knowledge this research project is the original work of the candidate, Dr Ng Chai Nee (PUM 0351/11).

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LIST OF FIGURES

ABBREVIATIONS

DSM 5**:** Diagnostic and Statistical Manual

FTD: Frontotemporal dementia

DAT: Dementia of Alzheimer’s type

DAD: Disability Assessment for Dementia

MMSE: Mini Mental State Examination

BPSD: Behavioral and Psychological Symptoms of Dementia

ZBI: Zarit Burden Interview

CVA: Cerebrovascular Accident

IHD: Ishaemic Heart Disease

LIST OF TABLES

APPENDICES

ABSTRAK

FAKTOR-FAKTOR YANG MENYUMBANG KEPADA BEBAN PENJAGAAN DI KALANGAN KELUARGE PESAKIT DEMENSIA YANG MENGHADIRI KLINIK MEMORI HOSPITAL PULAU PINANG

Latar Belakang Kajian : Demensia ialah penyakit kronik yang menyebabkan kemerosotan daya ingatan dan kesukaran untuk melakukan tugasan yang biasa dilakukan. Ini menyebabkan pesakit bergantung sepenuhnya kepada penjaga di samping mengalami keresahan akibat daripada gejala-gejala demensia. Di jangka bahawa sebanyak 43% di kalangan penjaga mengalami isu beban daripada penjagaan pesakit demensia.

Objektif : Mengkaji faktor-faktor yang menyumbang kepada beban penjagaan pesakit demensia seperti; gangguan tingkah laku(BPSD), aktiviti kehidupan seharian (ADL), sokongan social, kemerosotan kognitif dan profil penjaga dan pesakit terhadap beban penjagaan

Metodologi : Kajian keratin rentas melibatkan 121 pesakit dan penjaga yang menghadiri klinik memori, Hospital Pulau Pinang. Beban penjagaan di nilai dengan Zarit Burden Interview dan faktor-faktor yang di nilai ialah akitiviti harian (DAD), fungsi kognitif (MMSE), sokongan social (MPSS), gangguan tingkahlaku (MvNPI).

Keputusan : BPSD seperti delusi ($p<0.001$), sikap acuh tak acuh ($p=0.052$), merayau ($p=0.022$), sokongan social ($p<0.001$), tahap kolesterol ($p<0.001$) adalah berhubung kait dengan beban penjagaan

Kesimpulan :Beban penjagaan pesakit demensia tidak boleh di pandang ringan kerana ianya menyebabkan peningkatan dalam kos penjagaan pesakit dan risiko institusi . Oleh yang demikian, saringan awal ke atas penjaga dengan mengamallkan langkah pencegahan pada peringkat awal pada adalah wajib untuk mengelakkan kesan sampingan terhadap penjaga.

ABSTRACT

ASSOCIATED FACTORS OF CAREGIVERS BURDEN IN DEMENTIA PATIENT ATTENDING MEMORY CLINIC IN HOSPITAL PULAU PINANG

Background: Dementia is a chronic neurodegenerative disease characterized by memory impairment associated with loss of functional disabilities in the presence of consciousness. As the disease progresses, patient will become more dependent on their informal caregivers This study result showed that about 43% experiencing mild to moderate burden while caring for dementia patient.

Objectives: This study was to determine the associated factors that contributed to the burden of care in our local settings.

Methodology: A cross sectional study involving a total of 121 patients informal caregivers dyad which were recruited at memory clinic in Hospital Pulau Pinang. The outcome measure was Zarit Burden Interview and associated factors of burden were measured using Mini Mental Status Examination (MMSE), Disability Assessment of Dementia (DAD), Multidimensional Perceived Social Burden Scale (MPSS) and Malay Version Neuropsychiatry Inventory (MvNPI).

Results: We managed to find an association between behavioral and psychological symptoms of dementia namely; delusion ($p<0.001$), apathy ($p=0.052$), wandering tendency ($p=0.022$), dyslipidemia ($p<0.001$), hours of caregiving ($p=0.011$) and perceived social support from significant others ($p<0.001$) associated with burden of care.

Conclusion: Burden of care cannot be underestimate due to the risk of premature institutionalization and an increased in the health care cost. Therefore, early detection and prevention are mandatory to prevent deleterious effects on the caregiver.

CONTENTS PAGE

ABSTRACT

CHAPTER THREE: OBJECTIVES AND RESEARCH HYPOTHESIS

CHAPTER FOUR: METHODOLOGY

CHAPTER FIVE: RESULTS

APPENDICES

CHAPTER 1: INTRODUCTION

According to the World Alzheimer’s Report 2014, the number of ageing population diagnosed with dementia surpluses as the year goes by. This can be attributed to the increased in the elderly population in relation to the younger population in United States (Alzheimer's Association, 2014). There were 5.2 millions of elderly patients diagnosed to have Alzheimer’s disease in 2014. This figure is further supported by by Chicago Health and Ageing Project (CHAP) in 2010 which predicted around 5 millions of Americans were diagnosed to have Alzheimer’s disease. Of these figure, it was postulated that 11% are aged more than 65 years old while 82% from this figures are 75 years or older (Hebert, Weuve, Scherr, & Evans, 2013). This figure raised dramatically as shown by the Aging, Demographics and Memory Study (ADAMS), whereby there were only 13.9% of those 71 years old are estimated to have dementia as compared to the current figure (Plassman et al., 2007).

The Alzheimer Disease International predicted that the number of people diagnosed with dementia are expected to reach 115 millions by the year 2050. The prevalence of dementia in Malaysia ranges between 24% to 36.5% (Al-Jawad, Rashid, & Narayan, 2007; Sherina, Rampal, & Mustaqim, 2004). According to the Alzheimer’s Disease Foundation of Malaysia, the figures that are being captured through various studies and formed part of the iceberg phenomenon. As such, it is believed that many are still under diagnosed due to the lack of knowledge regarding the disease. The increased in the prevalence rates can be attributed to many factors such as obesity and diabetes, longer life spans, an increased in survival rate after stroke and heart disease.

As the disease progresses, there are a wide range of symptoms experienced by the patient such as the behavioral and psychological symptoms of dementia (BPSD). Studies conducted, and found at least 75% to 80% of the demented population experienced at least one of these distressing symptoms (Lyketsos et al., 2002; Tampi, Williamson, & Muralee, 2011). These symptoms eventually limits a person's ability to function and hence, caused negative consequences and an overwhelming stress to the caregivers (Donaldson, Tarrier, & Burns, 1997). Based on a study conducted in Turkey, it was estimated about 90% of caregivers had some degree of burden. Those that were experiencing the caregiving strain had 63% risk of higher mortality as compared to the control groups (Grant et al., 2002). In Asia, Lim et al 1999 found that about 49% of caregivers of patients with mild to moderate dementia experienced the burden during caregiving. While in Malaysia, there were no data available regarding the prevalence of burden of care.

Since the disease runs a progressive and irreversible course coupled with the delay in seeking for treatment; both added on the detrimental effects to patients, caregivers and the society (Bradford et al., 2010; Donaldson et al., 1997; J J Dunkin & Anderson-Hanley, 1998). The World Alzheimer Report 2010 further supported this; whereby it is estimated that the total worldwide cost of dementia had exceeded USD 600 billion as compared to 10 years ago, which was only USD18 billion. In terms of the caregiving process, family and caregivers were acknowledged as the cornerstone of support for people with dementia and in return, this group of people experienced considerable amount of psychological and economic strain.

Therefore, caregivers' role in the process of caregiving cannot be underestimated. Based on the previous literature review, we were aware that caregiver burden stemmed from a complex interplay between both patient and caregivers variables. Long-term caregiving posed detrimental effects on the caregivers. Hence, this study was aimed at exploring the associated factors that contributed to the burden of care. Although there were numerous studies exploring on this field, however, local data were still sparse. Since there were limited local data pertaining to predictors of caregivers burden in dementia patient, it is hope that this study can provide some important findings that can reflect on the local population to facilitate early intervention catered for both patients and caregivers. Besides that, by early identification of the distress symptoms, it is hope that specific programs and services can be tailored according to the caregivers needs to alleviate the burden and baffled the above-mentioned consequences (Ory & Schulz 1999).

CHAPTER TWO: LITERITURE REVIEW

According to Zarit et al, burden of care can be defined as ‘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’. As cognition declined, dementia patient required an additional assistance to aid in their activities of daily livings. In other words, the levels of dependence on their caregivers correlate positively with the burden of care.

Zarit Burden Interview has been used to measure the burden of care in most of the studies. Studies showed that most of the caregivers were stressed out during the caregiving process when taking care of those patients who exhibited a wide range of behavioral and psychological symptoms (BPSD) of dementia since it was estimated that around 60% to 70% of dementia experienced BPSD symptoms at one point of their illness (Malhotra et al., 2014; Risco et al., 2015). In addition to the BPSD symptoms, there were other factors that contributed to the burden of care such as severity of the cognitive impairment as well as activities of daily livings. However, established studies found mixed results regarding contribution of these variables on caregivers burden (Kim, Chang, Rose, & Kim, 2012; Nip, JSW Lee, TCY Kwok, 2010).

Burden arising from the caregiving process gave rise to both psychological and physical morbidity to the caregivers. Physical morbidities such as higher rate of psychotropic drugs consumption, alcohol usage, impairing immune system which resulting in poor self-rated health. In terms of psychological morbidity, caregiving process can caused an increased risk of developing stress, family conflicts, social isolation, which later on can precipitate the development of depression.

Despite of the negative consequences, some informal caregivers can experience positive effects from caregiving as well such as experiencing satisfaction from their efforts. Those informal caregivers who had protective factors like good social support has been shown to reduce burden of care in the caregiver (Choo et al., 2003; Nurfatihah, Rahmah, & Rosnah, 2013). Other factors like presence of resilience in the informal caregiver were associated with lower level of burden and a better psychological well being (Dias et al., 2015). In addition Fauth et al 2012 had concluded that the closer the relationship between informal caregivers and care recipients, the lesser the burden of care.

Other factors like social demographic variables such as age, gender, ethnicity, level of education; presence of any co morbid medical illness and its relation to burden of care will be discussed and further explored.

2.1 Burden of care in dementia with behavioral and psychological symptoms of dementia (BPSD)

Behavioral and psychological symptoms of dementia comprised of a group of heterogeneous symptoms. It is characterized by 12 behavioral and psychological symptoms; namely; delusions, hallucinations, agitation/aggression, depression, anxiety, euphoria, apathy, disinhibition, irritability, aberrant motor behavior, sleep disturbances and appetite change. Studies have shown that the prevalence of BPSD in dementia patients ranges from 80% to 90% (Margallo-Lana et al., 2001; Neil & Bowie, 2008; Tampi et al., 2011). Studies shown that both direct and indirect costs in caring for a person with BPSD ranges from 25% to 35% of the total annual costs required in looking after a demented patient (Beeri & Noy, 2002; Tampi et al., 2011).

Since BPSD formed an integral part in the diagnosis of dementia, numerous studies had been carried out to ascertain its relationship with caregivers burden. Most of these studies found that BPSD contributed significantly to the caregivers burden(Allegri et al., 2006a; Huang et al., 2010; Onishi et al., 2005). In view of its importance, studies nowadays had focused on the individual symptoms that contributed individually to the burden of care. Studies found that agitation, dysphoria, irritability, delusions, apathy and aberrant motor behavior were associated with the burden of care (Kaufer et al., 1998; Matsumoto et al., 2007).

Another similar study was done in Taiwan, involving 88 caregivers who were recruited from January 2007 to December 2007. In this study, BPSD symptoms were assessed using Neuropsychiatry Inventory-D scale. They found that delusion was the most important feature contributing to the burden of care in addition to agitation/aggression and irritability and lability (Huang et al., 2010). From the study conducted in Thailand, the author found that, 90.5% of 158 patients had at least one BPSD symptoms. During this study, BPSD were measure using Thai version of NPI-Q, Global Clinical Dementia Rating Scare and Mini mental state examination (MMSE). The study summarized the common findings that are almost similar to those mentioned earlier. As such, symptoms like agitation/aggressive behavior; disinhibition and sleep problems contributed more to the burden of care as compared to irritability, depression and anxiety(Taemeeyapradit et al., 2014). Although there were many international studies had depicted that BPSD caused an enormous burden in the caregiver, local data are still very much lacking; especially pertaining to caregiving in dementia. However, there was a local study conducted by Rosdinom et al in 2013 found that among the 65 caregivers involved, total BPSD scores contributed to the burden of care. Among these BPSD symptoms, apathy was reported the most common symptom observed at 83.2% followed by 60% who experienced agitation and 53.8% who had sleep disturbances in the local data (Rosdinom et al.,2013).

Since the burden of care has been well established and associated with a high prevalence rate, the burden arising from these symptoms should not be taken lightly. As the disease progresses, BPSD symptoms resulted in increased burden of care, negative implications on the caregivers and increased in the risk of institutionalization (Shin et al.,2005).In addition to this, the demand exerted on the caregiver has also been linked to adverse psychological distress and risks of developing mortality among the caregivers (Schulz & Beach, 1999; S H Zarit & Bach-Peterson, 1980).

Therefore, early recognition and management of BPSD symptoms can improved the quality of life of dementia patients and delayed transition from home to institutional care (Lawlor, 2002).

2.2 Burden of care in dementia with activities of daily livings

As the disease progresses, dementia not only contributed to behavioral and psychological symptoms, it also affects the physical functioning of the patient. As a result of this, demented patient became more dependent on the caregivers during the later stage of the illness. In a study conducted by Haley in 1989, the results of his study reflected that, among the 48 families who had been follow up during the initial stage of the illness, deterioration in the instrumental self care were more prominent as compared to decline in basic self care during the later stage of the illness (Haley & Pardo, 1989; Kim et al., 2012; Nip et al., 2010).

In a cross sectional study conducted in Hong Kong, researcher studied on whether functional disability contributed to the burden of care. The degrees of functional impairments were measured using the disability assessment scale for dementia (DAD) for 88 patients and their caregivers alongside with Barthel Index. The DAD scale was used as it was more specific for dementia patient in terms of evaluating both instrumental and basic activities of daily livings which covered 3 main domains; namely initiation, planning and organization as well as whether they can carry out the task effectively. This study concluded that 97% of demented patients had limitation in performing their instrumental activities of daily livings followed by 59% with impairments in their activities of daily livings. Besides that, other domains largely affected were planning and organization followed by ability to complete the task effectively (Nip et al., 2010). Other international studies had also echoed the similar findings (Miyamoto & Ito, 2010; Razani et al., 2007). For instance, in South Korea, author proposed that functional disability contributed to the enormous caregivers burden. As such, most of the caregivers' times were being occupied in assisting them with their disabilities and catering to their daily demands. This indirectly increased their dependence on the caregivers and resulted in poor quality of life (Kim et al., 2012; Serrano-Aguilar & Yanes-Lopez, 2006).

In another recent prospective cohort study conducted to see the association between physical dependency and neuropsychiatry symptoms among those staying under institutional care and home based patient, the findings shown that those staying in institution had more dependency on their basic activities of daily activities such as toileting, dressing and continence as compared to those home based. These domains of impairments also contributed to future risks of institutionalization apart from their neuropsychiatry components when their severity of dependency rises (Risco et al., 2015). In a recent study done in Singapore, looking at the association of BPSD and functional limitations as contributing factors in caregivers' depression had concluded that, both these factors had an association with the development of caregivers' depression (Malhotra et al., 2014). Therefore, early identification of the functional disability is vital to overcome this untoward consequence

2.3 Burden of care in dementia with cognitive impairment

The process of dementia involved progressive cognitive impairment occurring in clear consciousness. Although this manifestation is the earliest to manifest and are thought to be contributing to the burden of care, but results from other studies showed otherwise. In Japan, a study was conducted to compare the predictors of caregivers burden between those with amnestic mild cognitive impairment and mild Alzheimer's disease. The study replicated similar results from other studies whereby significant caregivers burden stemmed from behavioral and psychological symptoms of dementia as well as the degree of dependency on the caregivers but not the severity of the memory impairment. These burden are seen even in those caregiver who cared for the patient during the initial stage of mild cognitive impairment (Seeher et al.,2013; Yeager & Coyne, 2010). One of the reasons that contributed to the burden was perhaps due to the repeated questioning posed by the patients to the caregivers due to their failure to recall previous information (Hayashi et al., 2013). However, in another separate study conducted longitudinally in Europe; in terms of predicting the cause of burden, results shown that cognitive impairment contributes significantly to the caregivers strain apart from the behavioral and psychological symptoms and functional disabilities (Germain et al., 2009).

Contrary to the above findings, cohort study was conducted by researcher to look into predictors of caregivers burden in dementia patient. Among the 50 samples recruited, the proposed burden of care do not correlated with the cognitive status as measured by the mini mental status examination but rather the behavioral and psychological symptoms (Coen & Coakley, 1997).

Another study that echoed the similar findings was by Ricardo et al in 2006. In his study, 82 patients were recruited and their cognitions were measured by mini mental status examination besides assessing other prominent factors that contributed to the burden such as BPSD symptoms. Their conclusion was burden of care was not related to the degree of cognitive impairment (Allegri et al., 2006a). Although there were sparse findings locally, however, one cross sectional study was carried out in Hospital University Kebangsaan Malaysia and Hospital Kuala Lumpur in 2007 involving a total of 65 patients. The aim of the study was to explore on the relationship of burden of care with and their cognitive function. Baseline cognitions were measured by MMSE. They were unable to establish the relationship between the burden or care and the severity of cognitive impairment(Rosdinom et al., 2013). Therefore, although deterioration in cognition is marked in the diagnosis of dementia, but most studies found that, caregivers are more stressed handling their behavioral and psychological symptoms as well as their functional disability as compared to their cognitive deterioration.

2.4 Burden of care in dementia with perceived social support

Cohen and Wills 1985 proposed that social support and stress are inversely related to each other. According to them, social support acted as a strong buffering effect to protect an individual from the detrimental effects of caregiving or during a stressful event. There are a few researches that showed that the detrimental effects of caregiving can affect the individual both mentally and physically (Cohen, 2004; Pinquart & Sörensen, 2007; Schulz & Fleissner, 1995). Studies reported that, most of them that care for the dementia patients are at higher risks of developing mood symptoms like depression and anxiety symptoms. A study that echoed the similar finding was done in China in 2013. In this study researcher concluded that those family that look after dementia patients are likely to have low social support as a result of damaged to the family functioning (Zhang et al., 2013). Besides psychological impact, caregivers are also exposed to other physical complications like higher stress hormones and impaired immune system(Mahoney & Livingston, 2005)

Informal caregivers; especially those of immediate family members of the patients played a vital role in the caregiving process. The dynamic relationship between the caregivers and the patients are often severed during the caregiving process and this can be due to many factors. Although researchers found that, most often the lack of knowledge or skills in caring for these group of patients often the main reasons but more often than not, the role of social support has been underestimated. In addition to the social support, personality of the caregivers such as their coping skills, adaption skills and problem solving can also foresee their burden (Zarit & Bach-Peterson, 1980a). These mentioned factors from the caregivers should be properly addressed in order to prevent caregivers morbidity and early institutionalization (J. J. Dunkin & Anderson-Hanley, 1998). According to Sarason et al 1991, the instinctual feelings of perceived social support is important in the sense that, it served to buttress the caregivers emotionally where they felt wanted and perceived that assistance is available when they needed it. Therefore, although other factors are equally important but in this study, relationship between perceived social support from the informal caregivers and burden of care will be explored.

In view of the importance of social support acting as buffering effects, a few studies had been conducted to support this hypothesis. A recent study in China was conducted looking at the caregivers' burden and the associated factors. A total of 152 families were being interviewed and assessed using the Social Support Rating Scale found that those with more social support reported less burden (Wang & Ullah, 2015).

In accordance to the above findings, there were also a few local studies, which echoed the similar findings. In a study conducted by Choo and colleagues, in assessing the factors associated with caregivers burden, the researcher highlighted the importance of equipping the caregivers with proper coping skills in addition to adequate social support in lessening the burden of care (Wan-Yuen Choo et al., 2003). On the other hand, in another separate study conducted locally, researcher assessed the perceived social support on 145 informal caregivers using the validated Malay version of multidimensional perceived social support questionnaires, assessing the supports mainly from 3 domains which were; significant others, family and friends. They were able to conclude that most informal caregivers who experienced less burden received the informal support from family mostly (Nurfatihah, Rahmah, & Rosnah, 2013). Therefore, in this study, further association of importance of perceived social support and the burden of care will be further explored.

2.5 Burden of care in dementia with informal caregiver characteristics.

The burden of care can be caused by multiple factors such as those being mentioned earlier. Apart from the illness itself, characteristics of the caregivers itself also played an important role in determining the burden of care. Caregiving can be a tedious job for the caregivers and therefore, efforts made in identifying the sociodemographic factors as one of the independent variables can help to detect those caregivers at risks of developing the burden through the caregiving process. Most of the time, caregiving process is being provided by their significant others or their children mostly. A few studies concluded that, mostly female counterparts are more frequently associated with burden of care as compared to male counterparts (Kim et al., 2012; Mehta, 2005; Torti & Schulman, 2004). This is because, traditionally female are born to have an ‘innate feelings of caring ‘for others(Kua &Tan, 1997).

While this explanation may seem logical, other study had postulated that different genders coped differently and perhaps this is also another point, which is worth to look at. Male caregivers adapt by acceptance and with problem focused coping while the females focused more on emotional coping (Almber & Winblad, 1997). However, there were also other studies which shown no difference between burden of care between the genders (Baker & Connelly, 2010; Baker & Robertson, 2008; Kua &Tan, 1997). With respect to age, there were mixed findings noted. Some observed that those caregivers who were younger were also afflicted with more burden while other study found older caregivers were more burdened (Ampalam & Padma, 2012). One explanation to this is; as age advances, caregivers are having more difficulty in coping with the caregiving processes due to their advanced age and also other added responsibilities.

Apart from gender, education status also played a vital role in predicting the burden of care. A study conducted in Netherlands found that, the burden is less in those caregivers who were more educated than those who were not. This was because the educated group utilized more of supporting strategy and thus, able to meet the demands imposed by the patients on them(De Vugt et al., 2004).

However, there is also another study, which proved otherwise. Participants with lower education are deemed to have fewer burdens. This can be explained by a simple principle whereby; less educated people were more contented with their life and had lower expectations in life as compared to higher educated people (Kramer, 1997). However, our local study by Rosdinom et al in 2008, education level was not significant in contributing to the burden of care. Apart from that, her study also revealed that, there were no difference in terms of the burden of caregiving in between the races and and marital status.

Research on marital status showed a somewhat controversy results. Some found that being unmarried; especially women posed a higher risk of developing caregivers burden (Choi & Bohman, 2007) and at the same time, those who were married were not exempted from the burden of care either (Diel & Chaves, 2010).

Over the years, studies depicted that chronic stress imposed on the caregivers through the caregiving process can caused unwanted metabolic symptoms (Pyykkönen et al., 2010). This is because caregiving is a process that required commitments and is time consuming process. Therefore, caregivers often neglect their health through deprived sleep and living a sedentary lifestyles as most of their time were devoted for caregiving (Fuller-Jonap & Haley, 1995; Gallant & Connell, 1997). According to Pyykkonen 2010, the stressful life events explained the reason for insulin resistance, obesity and accumulation of triglycerides. Therefore, in this study we were looking at whether the presence of medical illness such as diabetes mellitus, hypertension, ischemic heart disease and dyslipidemia had any contribution to the existing caregivers burden. Another study done by Brennan in 1996 found that, long term stress causes release of catecholamine-stimulated free fatty acid which in return causes stress induced hypercholesterolemia (Brennan & Maier, 1996).

In addition to that, anger stemming from the caregiving process were thought to elevate the blood pressure, increased fasting blood sugar as well as increased in fat intake which later on, predisposed the caregivers to medical morbidities (Scherwitz & Chesney, 1991; Shapiro & Jamner, 1996). Therefore, in this study, we incorporated these medical illnesses to see the significant in contributing to burden of care.

2.6 Burden of care in dementia with patient characteristics

Besides that, patient characteristic also played a substantial role in the burden of care. For example, the perceived burden of care can be influenced by the type of dementia the patient is having. According to a study conducted by de Vugt et al 2006, he found that caregivers perceived more burden in taking care of patients with Fronto-temporal dementia as compared to Alzheimer's disease. This can be understood as; those suffering from Fronto-temporal dementia were usually younger onset and suffered more disabilities in terms of their instrumental activities of daily livings and more disabling as compared to Alzheimer's disease.

Caregiving usually being carried out by someone who was supposedly closed to the patients, such as being their spouse, children or siblings. In other studies, researcher found that both spouses and children experienced a higher burden score as compared to other family members who are also involved in the caregiving process(Conde-Sala & Turró-Garriga, 2010; G.Karlikaya, 2004). This is because; spouses assumed their role as part of marital duties while children fulfilled their responsibilities to care for their elderly parents.

Next, we are exploring whether patient who were on treatment were associated with burden of care. Research established that, treatment with cholinesterase inhibitors such as donepezil improves the activities of daily livings in the patient and therefore, diminished the time spent assisting the patients. This indirectly reduces the caregivers burden (Feldman et al., 2003; Marin et al., 2003; Shikiar et al., 2000). On the other hand, antipsychotics and antidepressants have been documented to reduce the caregivers' burden as well, but results were inconsistent thus far due to variability in the study measure (Levy & Lanctôt, 2012). Therefore, in this study, we were trying to establish an association between caregivers burden and the respective characteristics.

CHAPTER THREE: OBJECTIVES AND RESEARCH HYPOTHESIS

3.1 General Objectives

To determine the associated factors of caregiver burden in patient with dementia

3.2 Specific Objective~~.~~

1. To determine the prevalence of caregiver's burden in dementia patients
2. To determine the association of behavioral and psychological symptoms of dementia towards caregivers' burden.
3. To determine the association between activities of daily livings with caregivers' burden.
4. To determine the association of perceived social support in contributing to the caregivers' burden.
5. To determine the association between severity of cognitive impairment with caregivers' burden.

3.3 Research Questions

3.3.1 What are the prevalence of informal caregivers burden?

3.3.2 What is the association between behavioral and psychological symptoms of dementia with caregivers' burden?

3.3.3 What is the association between activities of daily livings with caregivers' burden?

3.3.4 What is the association between cognitive impairment with caregivers' burden?

3.3.5 What is the association between perceived social support and association with caregivers' burden?

3.4 Research Hypothesis

1. There is an association between caregivers' burden and behavioral and psychological symptoms of dementia.
2. There is an association between caregivers' burden with activities of daily livings
3. There is no association between caregivers' burden with severity or cognitive impairment.
4. There is an association between caregivers characteristic factors and caregivers' burden
5. There is no association between patients characteristic factors and caregivers' burden
6. There is an association between caregivers' burden and perceived social support.

CHAPTER FOUR: METHODOLOGY

4.1 Research Design

This is a cross sectional study conducted in the outpatient Psychogeriatric and Memory Clinic in Hospital Pulau Pinang and inpatient psychiatry ward at Jalan Perak from the period between December 2014 to May 2015. The psychogeriatric clinic was held on every Tuesday and Thursday morning as well as on Wednesday afternoon while the memory clinic was held on every alternate Monday afternoon. Hospital Pulau Pinang is the tertiary hospital and is the only hospital in the northern region that provides the services for psychogeriatric populations. The inpatient unit caters for those who required admission from the northern region as well.

4.2 Populations and Sample

4.2.1 Reference Population

Patients diagnosed with dementia

4.2.2 Source Population

Those patients diagnosed with dementia attending Psychogeriatrics and Memory Clinic with their caregivers in Hospital Pulau Pinang are recruited. Hospital Pulau Pinang was chosen as a centre for sample collection mainly due to logistic reasons as the author was posted to Hospital Pulau Pinang as part of her rotation. In addition to that, the psychogeriatric service provided in the hospital caters for a large perimeter of population in the northern region. Therefore, this ensured a stable flow of patients from all walks of life for a smoother recruitment process.

4.3 Sampling Frame

All dementia patients and their caregivers who were attending Psychogeriatrics, Memory and Memory Clinic at Hospital Pulau Pinang and fulfilling both the inclusion and exclusion criteria were recruited during the period of study.

4.4 Inclusion Criteria

A) Patients

- Diagnosis of dementia made based on DSM 5.
- All patients receiving treatment in Memory and Psychogeriatrics Clinic in Hospital Pulau Pinang.
- Mini mental state score of 24 or less.

B) Informal Caregiver

Informal caregiver is defined as an unpaid individual (spouse, partner, family members, friend or neighbor) that provide unpaid care and involved in assisting others with their activities of daily livings and or medical tasks (Family Caregiver Alliance, National Centre of Caregiving, 2009, Mittelman, 2003). According to American Psychological Association, caregiving is defined as minimal assistance of care provided by the caregiver for at least 4 hours per day. Caregiving is defined as caring for an adult disabled person, which is outside the norm of expectations for older adults (Patricia, 2007)

- Age at least 18 years.
- Ability to speak Malay language and or English language.